

RESEARCH ARTICLE

“Social Media has Opened a World of ‘Open communication:’” Experiences of Adults with Cerebral Palsy who use Augmentative and Alternative Communication and Social Media

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Abstract

An online focus group was used to investigate the experiences of nine individuals with cerebral palsy who use augmentative and alternative communication (AAC) and social media. Information was gathered related to (a) advantages of social media, (b) disadvantages of social media, (c) barriers to successful use, (d) supports to successful use, and (e) recommendations for other individuals using AAC, support personnel, policy makers, and technology developers. Participants primarily chose to focus on social media as a beneficial tool and viewed it as an important form of communication. The participants did describe barriers to social media use (e.g., technology). Despite barriers, all the participants in this study took an active role in learning to use social media. The results are discussed as they relate to themes and with reference to published literature.

Keywords: *Social media; Augmentative and alternative communication; Cerebral palsy; Focus group; Internet; Assistive technology*

Introduction

Communication is our connection to humanity and the “essence of human life” (Light, 1997, p. 61). Gamble and Gamble (2013) described communication as, “. . . a process involving the deliberate or accidental transfer of meaning. One person does or says something, thereby engaging in symbolic behavior, while others observe what was done or said and attribute meaning to it” (p. 2). The ways individuals are communicating, talking, and thinking about communication is changing as a result of social media (Baruah, 2012). Research in the area of AAC has historically focused on developing best practices to support the building of strategic, operational, linguistic, and social competence (Light, 1989) through face-to-face communication interactions in group, individual, or generalized settings. Yet advancements in technology have opened new communication environments and modalities for individuals with and without disabilities.

Individuals who have disabilities and use augmentative and alternative communication (AAC) expect to be full participants in our society (Blackstone, Williams, & Wilkins, 2007). While changes in mainstream tech-

nologies have presented new opportunities for many individuals who use AAC, they have not always resulted in improved access to these opportunities (DeRuyter, McNaughton, Caves, Bryen, & Williams, 2007). Full access to the internet, email, cell phones, as well as social media, are fundamental communication activities in the 21st century and support full participation in society (DeRuyter et al., 2007).

Social media refers to a set of online tools centered around social interaction. This can include discussion forums (e.g., Phorum¹, Yelp²), social sharing services (e.g., YouTube³, Flickr⁴), text messaging, and social networking services (e.g., Facebook⁵, Myspace⁶, LinkedIn⁷) (Bertot, Jaeger, & Hansen, 2012). The number of people who participate in social network sites has grown rapidly over the past 5 years. As of May 2013, in the United States, 72% of online adults use a social networking site of some kind. Facebook is the dominant social networking platform by number of users as 71% of online adults are Facebook users. Users have also begun to diversify to other platforms, with 42% of online adults concurrently using multiple social networking sites (Duggan & Smith, 2013).

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Individuals with disabilities exhibit far lower levels of Internet use compared to those living without disability. Fox and Boyles (2012) found that individuals who reported having a disability used the Internet at lower rates than those who did not (54% vs. 81%). Lower levels of Internet use are found irrespective of age. DeBell and Chapman (2006) reported reduced Internet use within groups of young people with disabilities in comparison to non-disabled peers. Raghavendra Wood, Newman, and Lawry (2012) carried out

qualitative interviews with 15 children with disabilities and found the Internet was used for a variety of purposes, but the extent and frequency of use was lower than for peers without disabilities. Internet access remains unequally distributed, as individuals living with disabilities do not engage in networked society at the same rate as individuals without disabilities. The growth of the Internet, and the proliferation of tablets and smart phones, have changed the ways people communicate, work, and learn, while at the same time increasing the isolation of those who do not have access (Foley & Ferri, 2012).

Social media can be used for individuals with and without disabilities to communicate thoughts, share and gather information, maintain and grow relationships, and develop social networks. There is a growing body of research about disabilities and social media use (e.g., Baker, Bricout, Moon, Coughlan, & Pater, 2013; Barnfather, Stewart, Magill-Evans, Ray, & Letourneau, 2011; Lewis, 2010; Shpigelman & Gill, 2014), yet currently there is very limited research investigating whether individuals with complex communication needs use social media sites for communication, social participation, leisure, and learning opportunities. Raghavendra and colleagues (2012), through interviews of 15 adolescents ($M_{age} = 14.6$), found the Internet was used for a variety of reasons, including: emailing,

instant messaging sites, social networking sites (e.g., Facebook) and gaming. The participants highlighted the benefits of using social networking and that friends/siblings played a significant role in supporting the set up of social networking sites.

Hynan, Murray, and Goldbart (2014) interviewed 25 adolescents and young adults (ages 14-24) who used AAC about their use of digital technology and online social media. Participants expressed how social media helped them to keep in touch with people, be understood by others, and express themselves more fully (e.g., show humor, share narratives). The main barriers to independent use of social media were lack of access to equipment, mobility issues, and limited literacy skills. Despite these preliminary studies on the experience of adolescents who use AAC, there is currently no research on the experiences of social media use by adults who use AAC.

This study contributes a new dimension to the limited body of research and reflects the societal trend of broad ages participating in social media, not just adolescents. At the present time there is limited understanding of the potential benefits and unique barriers that social media usage presents to adults who communicate using AAC. Given the potential importance of social media in the lives of adults who use AAC and the lack of research to date, the current study elicits the views of people who use AAC, specifically the

experiences of adults with cerebral palsy. To expand current understanding, nine adults with cerebral palsy ($M_{\text{age}} = 43.88$) who use AAC were invited to participate in a focus group to share their experiences regarding successful use of social media sites. Specifically, the study aimed to investigate (a) advantages of social media; (b) disadvantages to social media; (c) barriers to successful use; (d) supports to successful use; and, (e) recommendations for other individuals using AAC, as well as support personnel, policy makers, and technology developers.

Methods

Research Design

The study used a qualitative research design involving a focus group. Qualitative research designs are appropriate for exploration of new phenomenon in an attempt to understand the unique interactions and experiences that occur within a particular situation (Tracy, 2012).

Previous research related to social media use by individuals who use AAC utilized the qualitative methodology of individual interviews. In contrast to individual interviews, focus groups methodology capitalizes on the communication between the participants as an important source of data (Tracy, 2012). Focus group methodology has been used in the past to understand perceptions of people using AAC and was chosen for this study in order to develop an understanding of social media usage

and experiences of individuals who have cerebral palsy, have basic literacy skills, and who use AAC.

Focus groups typically take place in one setting, consist of six to 10 participants plus a moderator, and take several hours (Tracy, 2012). An asynchronous on-line focus group was used (Stewart & Williams, 2005), as this forum allowed the nine participants to engage in discussion despite their dispersed geographic locations, participate in the discussions at their personal communication rate, and contribute to the discussions during times that were convenient for them (Stewart & Williams, 2005). The online focus group was modified from traditional focus group techniques following the approach used by McNaughton, Light, and Groszyk (2001).

Participants

Recruitment. Ethics approval was obtained from the Human Research Protection Program prior to commencement. Participants were recruited through direct contact with individuals who use AAC, SLPs, and other professionals who work with individuals who use AAC. The aforementioned individuals were contacted through (a) web posting (i.e., an Internet listserv where SLPs or individuals who use AAC communicate), (b) social media (e.g., Facebook and Twitter⁸), and (c) emails. In all situations, interested participants were asked to contact the first author via email. When participants inquired about involvement,

they were emailed with detailed information regarding the study objectives, requirements, and information about the password-protected Wikispace⁹. Participants gave informed consent by creating a user name and logging into the Wikispace created for the purpose of this research.

Criteria for participation. In order to participate, individuals were required to (a) be over the age of 21; (b) have cerebral palsy; (c) have complex communication needs, whereby their speech was inadequate to meet all their daily communication needs and AAC was used; (d) have functional literacy skills (i.e., spelling and written skills that allowed them to produce and understand text-based messages); (e) have Internet access and means to participate in a text-based discussion online; (f) use, at a minimum, one form of social media (e.g., Twitter, Facebook, Snapchat¹⁰, IM¹¹) at least 3 times per week; and (g) be willing to commit to an online forum for 6 – 8 weeks.

Participant description. Table 1 presents demographic information for the study participants. A total of nine adults were involved in the focus group discussion. Participants included two women and seven men, ranging in age from 23 to 67 years. All had been diagnosed with cerebral palsy and had complex communication needs requiring the use of AAC to support communication needs. Eight of the participants lived in the United States and one lived in New Zealand. As seen in Table 1, the

participants used a variety of social media sites, yet all identified Facebook as their preferred social media site.

Insert Table 1 About Here

Materials

The focus group discussions were conducted online using a password-protected Wikispace. A Wikispace is a website that allows for creation of simple interactive webpages and collaborative knowledge communities. This format was selected due to its easy authoring; that is, the ability to quickly publish new content and comment on existing posts. The Wikispace allowed participants to post text-based discussions of various topics, read the information posted by other participants, and contribute comments and ideas on posts within one main page. The topics and questions posted to the Wikispace were identified before the focus group began. Questions were developed through a review of the literature related to social media and Internet use of individuals with and without disabilities. The literature review was used in two ways for question development (Law, 2004): First, it assisted in choosing questions that addressed gaps in the current research and future research directions identified by researchers (e.g., Shipigelman & Gill, 2014). Second, it was used to gain insight on the types of researchable questions that have been used successfully in related research. Prior to the start of the focus group

discussions, the questions were reviewed by colleagues with AAC experience to confirm their relevance. See Appendix A for full text of the questions used.

Procedures

Once participants had provided their consent to participate, they were emailed questions to obtain background information about how they use social media, communicate, and physically access their AAC devices. Upon returning the completed background questionnaire, an e-mail message was sent reiterating participation requirements and providing instructions to use the Wikispace. Specifically, the participants were asked to (a) visit the discussion site two to three times per week, (b) contribute to each topic's discussion, and (c) be respectful towards all other participants. The participants were asked to post an introductory message (three facts about themselves) and comment on a group member's post. This ensured their successful use of the Wikispace. After all participants had posted their introductory messages, the moderator presented the first discussion topic. A new topic was introduced on the site after the majority of group members responded to the discussion (approximately every four to seven days).

The procedures for the focus group were adapted to meet the challenges of an Internet-based focus group discussion based on prior research by

McNaughton et al. (2001) by (a) creating a password-protected website for the focus group, (b) starting a new discussion thread on the website and posting questions to the discussion, (c) managing the discussion, and (d) allowing members to check to see if their view was reflected in a summary of the discussion. The first author was the system administrator and moderator. This included the responsibility for maintaining the Wiki (e.g., protection and deletion of accidental multiple posts), presenting the discussion topics, and regulating the discussions as needed (i.e., requesting participation, commenting, adding a probing question (Stewart & Williams, 2005).

The focus group continued for a six-week period. After six weeks, participants were reminded via email that the forum was closing and were asked to post messages for all topics if they had not already done so. Approximately 3 weeks after the final posting, an email was sent to all participants thanking them for their participation and summarizing the themes and sub-themes discussed on the site. This email served as a member check (Tracy, 2012), giving participants the opportunity to read the summary and validate it as an accurate representation of the discussion. All nine participants confirmed that the summary was accurate and complete, and no additional comments were made.

Data Analysis

The participants' contributions to the discussion pages were "unitized" by the first author, meaning the text was broken up into "...the smallest amount of information that was informative by itself" (Vaughn, Schumm, & Sinagub, 1996, p. 106). These units were typically a single phrase or sentence (e.g., "social media has become such a normal way to stay in touch with people"). Units were reviewed and organized into themes (e.g., advantages of social media) and subthemes (e.g., connection with others) based on topics and content. These coding themes were developed post hoc based on a review of the participants' contributions. Operational definitions were then created for the coding themes (Vaughn et al., 1996; Tracy, 2012). Five major themes were identified related to the topic at hand, the use of social media. Three additional themes were also defined. These themes included extraneous comments unrelated to social media use (e.g., comments related to disability or AAC use in general).

Each theme was designated by a numeric code. These numeric codes were then assigned to the unitized data based on the content and the operational definitions. A reliability check was performed after all of the data were coded. A graduate student was first trained in the coding procedures. The graduate student coded and

received feedback on 20 text samples to ensure understanding of the coding procedures. Once the graduate students achieved greater than 90% agreement with the standard, a randomly selected sample, representing 20% of the unitized data, was independently reviewed and coded by the first author and the trained graduate student. Cohen's Kappa was used to measure inter-rater reliability. Cohen's Kappa takes into account the agreement that would be expected purely by chance, providing more information than the raw proportion of agreement (Viera & Garrett, 2005). The Cohen's Kappa agreement score was 0.90 and according to Everitt (1996), kappa values above 0.60 are satisfactory or solid agreements and values above 0.80 are regarded as nearly perfect agreements.

Results

During the 6-week period of the focus group, the participants posted a total of 118 times – a total of 8,122 words – to seven discussion topics. Seven of the nine participants posted responses for all seven questions posed by the moderator, one posted to five questions, and one posted to four questions. In addition to addressing the questions posed by the moderator, participants posted informal comments in reaction to the posts of others (e.g., “That's an awesome idea Matt” or, “I share the same problem as Walt and it's a shame as chat seems to be almost another way of instantly

talking”). They also posted a small number of questions (e.g., “Do you have CP too?” “What device do you use?”). Table 2 provides a summary of the themes, subthemes, and examples of specific issues discussed by the participants.

Insert Table 2 About Here

Advantages of Using Social Media

The participants expressed six main advantages of using social media: connecting with other individuals, feeling typical, making communication easier, gaining independence, getting help, and supporting employment.

Connecting with other individuals.

Participants discussed using social media in regards to maintaining relationships. As Matt commented¹², “You can keep everyone updated on what's going on in your life and keep up with their life. I believe that's a benefit [of social media].” Will made similar points, “For me, social media is wonderful. I can read and keep up with my family and friends from all over. In a few hours on Facebook I can talk to several people. I could never do that before joining Facebook.” Mark echoed Matt and Will's sentiments:

Since I got my latest AAC unit with its ability to use email and social media, I can now keep in contact with what is happening with friends and family almost instantly...I feel social media has helped me to maintain a lot more meaningful friendships, especially over a very long distance.

Participants also discussed how social media has facilitated the growth of relationships.

Will commented, “Me and this girl talk on Facebook but we didn’t meet on social media...we were classmates. The last 5 years on Facebook we have kept in contact...since seeing her [at a school reunion] we talk on Facebook almost daily.” Some participants shared experiences of how social media supported finding love, Mark said, “I found love on a social media site and after some time and much courage we decided to meet [in person]...now we are happily married.” Participants also indicated that they used social media to network with others. Matt said, “I believe social media is a valuable tool to network...I see this as another benefit for me.”

Feeling typical. The second subtheme involved thoughts on social media being a common way to communicate and a way to be included. As Pam explained, “[Social media gives me] a fair playing field. Instead of a wheelchair they see my thoughts.” Nicole said:

Social media has become such a “normal” way to communicate and stay in touch with people. There was a psychological aspect of being different in one more way [when using AAC]. Now everyone uses social media and walks around hooked up to some device like iPhones¹³, iPads¹⁴, etc. They [technologies] even have speech output sometimes like Siri! It helps to remember that everyone is communicating this way now, not just us.

Making communication easier. The third subtheme was widely discussed and focused on the participant’s use of social media to overcome

barriers that are faced when using other communication modalities (e.g., face-to-face and telephone). Mark said, “One could say social media has opened a world of “open communication” between people with speech impairments...” Participants reflected on the fact that social media is often a preferred communication mode. Kevin said, “I can’t speak...I will continue to use social media because it is the only way that I can really communicate well with people.” For the majority of participants, social media was reported to be an easier communication mode than face-to-face or telephone communication Chad said, “I wish I was born in this era. I would fit in better and probably have more friends because I communicate better on social media than face-to-face.” Other participants described their challenges with face-to-face communication and how they use social media to overcome many of these challenges. Matt expressed that, “Face-to-face conversation is difficult using AAC because we get ignored or walked passed. Social media can help overcome this.”

The participants also discussed the challenge posed by their slow rate of communication when face-to-face; they noted that social media was an effective means to overcome this challenge. Pam said, “[With social media] I have the opportunity to ACCURATELY represent myself to the world. The speed of communicating

is nonexistent.” Walt expressed similar beliefs, “It gives me time to compose my thoughts before I hit the post or send button.” Nicole described her experiences this way:

Social media gives me a chance to share things that I might not have had the opportunity to otherwise...Often in group conversations I am just a listener because I don't want to stop the conversation to make everyone figure out way I am saying [when using speech] or wait for me to type it out [when using AAC]...As an AAC user it provides me a good way to communicate and be included...without feeling like I am holding up everyone else.”

Participants also spoke about the challenges with communicating on the phone and how social media is an easier for them. Pam commented, “Calling someone is extremely difficult for me...posting on their wall or sending them a tweet is so much easier!” Kevin spoke of his challenges with using the phone to stay connected, “I can't talk, and therefore I can't use a phone. I was mad and sad because my friends couldn't call me...I use my computer like a cell phone now.” Mark discussed the ease of social media in connecting with others. He said: “I find I get more posts on social media than friends physically visiting or phone calls...With social media I can put up a post...instead of all the hassles that go with making multiple phone calls.”

Participants discussed how they perceived many of their communication partners as more comfortable communicating with them on social

media. Participants reported that people who were afraid to communicate in person were willing to get to know them through social media. Nicole explained that this gives individuals with disabilities an opportunity to be friends with more people. She posted, “It gives me a change to have friendships with people who would be somewhat afraid to get to know me in person. ...I know people from my past have felt more comfortable contacting me on Facebook than they would have in person.”

Gaining independence. The fourth subtheme focused on the role of social media in supporting individuals with disabilities to gain independence. The topic of independence and the benefits of social media were discussed by a number of participants. Kevin and Robert shared specific examples of wanting more independence and using social media to get this. Kevin wrote the following description, “When my wheelchair breaks, I can't call them [the company] myself to let them know...I am a very independent person... If they have Facebook...I would be able to get in touch with my wheelchair man myself.” Robert also discussed his experience: “I am able to maintain long distance friendships much easier [with social media] than letter writing. Traditional letter writing requires...putting on stamps and getting letters in a mailbox [things that I can't do

independently]... I can be independent using social media.”

Getting assistance. The fifth subtheme involved the use of social media to manage personal care and ask for assistance. Matt explained, “If I need something done, I can put it on there [Facebook] and see if anyone responds...I don’t have to call ten, twelve, or however many people to ask if they would be able to help me out.” Chad discussed a social media program he uses specifically to manage care: “I have a chat program called Trillian¹⁵...it has all chats in one program...I use it to get in touch with my attendants.” In addition to care, other participants use social media to get help and advice. For example, Will wrote, “If I need advice I can post a question and most times, within an hour, I will have a few answers.”

Supporting employment. The sixth and final subtheme of the advantages related to the use of social media to participate in work or to promote their own work. The discussion focused specifically on personal experiences with the use of social media in employment related activities. One participant said that she would not currently have a job without social media. Pam said, “[Social media got me] a job!!! I knew I would write for a living. With social media I can write with a modern twist!” Mike, Robert, and Matt addressed the importance of using social media to promote their

work. For example, Robert said, “Through Facebook I am able to promote my ministry and post Thoughts for Today.”

Disadvantages of Social Media Use

Despite the positive benefits of social media, participants also presented some disadvantages of using social media. Five subthemes emerged from the discussion: managing cyber security threats, lacking direct contact, lacking personal connection, lacking immediate responses, and over reliance on technology.

Managing cyber security threats. The first subtheme was about issues surrounding behavior in cyber environments and cyber security. Many participants discussed the lack of filter by social media contributors and reflected on concerns with cyber security. Chad described this, saying, “People write anything on social media.” Will said, “Social media is great, but it also can be dangerous and cruel.” Pam expanded on Will’s comments, saying, “There are obvious disadvantages to social media, such as, impersonation, bullying, etc...” Kevin went on to describe some of these concerns: “Somebody can make a fake page and pretend to be somebody else...someone can hack into your Facebook page and start talking to people [as you]...someone can take embarrassing pictures of you and put them on the Internet.”

Participants were concerned with trusting people online. Anonymity was often discussed as the root of trust issues. Mark said, “The main dislike I have...is members often don’t use their name...I realize this is to give protection, but it makes me suspicious of them trying to hid something.” Matt stated similar concerns: “A disadvantage is meeting people and then trusting them. Are they representing themselves to their true form? Who do you trust or not trust?”

Lacking direct/physical contact with others. In discussing this subtheme, participants highlighted the difference between interactions over digital media and those involving direct face-to-face contact. Walt commented, “There are advantages [to social media], but you can’t hug a person through the computer or iPhone.” The lack of physical contact was also discussed by Nicole, who said, “There are times when I wish for real contact. Many reflected on how the lack of direct and physical contact can be isolating despite being surround by many on social media networks. Matt discussed his thoughts on this: “I think the biggest disadvantage is the isolation of it. I know that sounds weird, but I think some can still feel isolated with using social media.” Mark commented, “The most obvious downside [for me] is the loss of socializing in person and often the physical isolation.”

Lacking personal connections. Several participants discussed the lack of personal connections when using social media. Nicole wrote, “I have heard many others discuss how social media limits real interactions...I think friendships [on social media] are less personal. Everyone posts things for the masses, so the personal ties don’t always come through.” One participant (Pam) discussed the lack of personal connection in relation to friend requests: “One negative experience is that if someone with a disability wants to friend me on Facebook just because we both have disabilities. I don’t like the assumption of we are both in wheelchairs, we should be friends,” she said.

Lacking immediate responses and reactions. A few participants discussed the lack of responses and reactions as a disadvantage of social media use. Matt summarized his experience, saying, “You can put something on there, but you aren’t going to get an immediate reaction like you would if you were discussing something in person.” Robert, who does ministry work and often communicates with people who don’t know him well, described his reaction when people initiate a conversation with him and then do not respond: “I hate being hung up on by people...they start a conversation...I respond to their small talk...I try to be patient...sometimes they never respond...it really irritates me...”

Over-depending on technology. The participants addressed the concern of over-reliance on technology. Although they all appreciated the benefits of technology to support communication and access social media, they also discussed concerns that individuals can become too engrossed in technology, forgetting about the people who are actually present with them. They noted that technology can also serve as a distraction from tasks they should be doing. For example, Chad commented, “People are on their cell phones twenty-four seven. They forget they are on the job.” Matt agreed and shared the viral YouTube video “Look Up¹⁶,” about stepping away from technology and living life through human interaction. He added, “I believe social media can be a good tool to help somebody establish relationships. I just don't want it to be taught as our only tool or way that we develop relationships.”

Barriers to Social Media Use

Although the participants discussed many benefits to using social media, they also highlighted barriers that prohibited their use. Three subthemes emerged: technology barriers, rate barriers, and access barriers.

Technology barriers. The first subtheme addressed the technology barriers that were encountered by participants when using social media. The barriers that were discussed by participants primarily focused on issues with their

AAC device interfacing with websites. For Matt, this was the only important barrier that he faced. He wrote, “A barrier for me...is making sure my device works on the site...” Robert commented with a more specific example on this issue: “[With the chat box feature on Facebook]...the other party can't see that I'm typing a message on my device to be sent eventually through the infrared Access It [so they don't know I am responding/typing].”

Rate barriers. Of most concern to the participants were rate barriers during instant messaging or chat sessions. Problems with virtual real-time communication were discussed frequently and for some, the only barrier mentioned. Pam said, “I haven't really encountered any barriers except for slow typing during an instant message session.” A few participants mentioned disliking, avoiding, or wanting to disable the chat features. Walt made reference to this. “I don't like to get on live chat because I don't type fast...so slow typing is my only barrier,” he said. Nicole also discussed her experiences with instant message sessions. “Since it takes me longer to type, I'm not comfortable communicating that way [instant messaging]. It is fine when they know me [to communicate via messaging], but when they don't it can be awkward because of slow typing.”

Physical access barriers. Participants raised issues concerning sites they would like to be on, but cannot access for reasons related to motor

control, as well as features within social media sites that are challenging. Pam and Nicole can't use mobile technology due to motor impairments, so applications that are created for those platforms are currently inaccessible to them. Mark and Nicole both commented on specific features that were difficult to use with their specific access methods. Mark said, "Any small buttons/links/tabs are so much more difficult when using an iPad/AAC with a hand pointer/palmer peg and shaky unsteady cerebral palsy hands." Nicole, who accessed social media through eye gaze said, "Volume [controls] on videos are not the easiest thing to control either...dragging the slider is also difficult for me."

Supports for Successful Social Media Use

Participants mentioned supports that may mitigate specific barriers and challenges. Three subthemes were identified in this topic: accessing social media using technology-based supports, educating communication partners, and taking appropriate safety measures.

Accessing social media using technology-based supports. This first subtheme included discussion of specific technology features to support the use of social media. Examples of this included use of programmable shortcuts (e.g., abbreviation expansions), prediction software, specific layouts on AAC devices, and web browsers. Participants viewed any shortcuts and

supports for speed and efficiency positively. Mark said, "I overcome barriers with iWordQ¹⁷ with prediction software...it has audio output so I can hear most spelling mistakes and it helps speed up my typing as well." Kevin commented, "Using EzKeys¹⁸ I can make shortcuts for any functions that I want."

The computer and AAC devices were the two main ways participants accessed social media. Will wrote, "I access Facebook through my computer...but [if needed] I can use my iPad which is also my AAC [system]." The majority of the participants described the benefits of the supports that are available on their dedicated communication devices. The devices provided them with instant access to their preferred social media sites and shortcuts that reduced operational demands. Nicole commented, "I use my AAC device to use social media...there is a page layout [on my Tobii¹⁹] that imports your newsfeed page and makes it easier to do things such as clicking like, etc."

Educating communication partners. Participants highlighted the value of educating communication partners with whom they interact on social media with for more successful exchanges. Participants mentioned reminding partners of strategies or explaining their AAC use. Partner education may help to lessen some of the previously mentioned barriers (e.g., rate barriers).

Will explained, “I tell people I type slow [before starting instant message] and then they understand.”

Taking appropriate safety measures.

Participants identified supports that could ensure safer use of social media as well. Examples of such supports were managing friend requests and being careful with what is posted on social media. The importance of safe computing was emphasized by almost all of the participants. Often times the advantages of social media were discussed with the caveat of using social media responsibly and cautiously. Will said, “You have to be careful who you accept as friends on Facebook.” Pam echoed Will’s comment: “If I don’t know you...I am not accepting your friend request.” Nicole also commented, “I don’t reveal any personal information with people whom I don’t know.”

Recommendations

All participants were successful users of social media, yet they reported that they had to overcome a variety of barriers to do so. In reflecting on their learning experiences and current social media usage, the participants provided recommendations for other individuals using AAC, support personnel, policy makers, and technology developers.

Recommendations for other individuals using AAC. The participants offered suggestions and advice for other individuals using AAC

regarding ways to learn to use social media and the different purposes of social media.

Recommendations included the need to explore on their own, to recognize how they want to use social media, and to make decisions based on personal preferences and needs. Many of the participants discussed the importance of knowing and understanding the different features available on computers and on their AAC devices. Mark said, “There are no [keyboard] shortcuts for posting from my iPad...there are programmable abbreviation shortcuts using a keyboard and PC. I sometimes use these to write lengthy sentences.”

Recommendations for support personnel.

The second subtheme entailed recommendations for teachers and therapists. The participants discussed how teachers and therapists should prepare individuals for social media use by explaining the proper and safe way to use social media and showing basic functions of the targeted social media site. Additionally teachers and therapists should provide assistance and help when barriers arise. Nicole said, “It would be nice to have teachers/therapists work with new users of AAC devices to show them any options that come with their devices including social media and any shortcuts that might be available.” Pam had a different take on how teachers can help individuals learn how to use social media sharing: “I think students are taught so many things by therapists

and school support staff...this is a good opportunity for teachers to set up ways to have students with disabilities to be taught by peers.”

Recommendations for policy makers.

Participants also discussed issues regarding funding. The majority of the participants were American and many of them expressed frustration with the funding regulations requiring AAC devices to be locked or Medicare-compliant models²⁰. They all strongly believed in funding of AAC devices, including the open or unlocked devices (which include access to such functions as the Internet, e-mail, telephone, social media, etc.). Will commented, “I don’t think policy makers should have the right to lock the Internet.” Nicole added, “I think we all agree that the locked vs. unlocked game we have to play is absolutely stupid...social media, email, and everything else...the way that EVERYONE communicates now requires an unlocked system.” Mark felt as though social media access was a vital part of a communication system, saying, “In regards to locked and unlocked issues, who would give someone a flashlight and find their way in the dark without any batteries.”

Recommendations for technology developers. The participants provided suggestions for AAC manufacturers and mainstream technology developers regarding ways to improve access and easier use of social media. The

recommendations for AAC manufacturers included suggestions for modifying AAC devices to facilitate social media use: For example, Will suggested, “I wish the delete button was down lower on my AAC device...more [pre-programmed] shortcuts for Facebook in my device would be great,” and Walt suggested “[Pre-programmed] common messages to send as replies would be good. The recommendations for mainstream developers ranged from ways to address barriers to ways to improve social media sites: For example, Mark recommended “More shortcuts for Facebook”, Robert suggested “A way to show I’m typing with the device [on the site]”, Nicole said “I wish the ‘like’ button of Facebook was bigger,” and Mark recommended “All links should be in upper case and in a contrasting color.” The participants also provided ideas for the future (e.g., Matt said, “I wish that social media platforms would include more video chats so that people can be face-to-face when they want.” Participants spoke of their interest in working with developers. As Nicole said, “I like the idea of working with developers for future versions of sites. It always bugs me that as new technology comes out people who use adaptive equipment usually have to wait until the assistive technology catches up.”

Discussion

Social media played an important role in the lives of all nine of the participants in this study,

each of whom described significant benefits. Specifically, they noted that social media allowed them to connect with others, feel more typical, communicate more easily, gain independence, get help, and complete various job-related tasks. Despite these benefits, the participants also highlighted some disadvantages to the use of social media: cyber security threats or bullying, the lack of direct contact and personal connections with others, the delay in responses via social media, and the over-reliance on technology to the neglect of face-to-face interactions. The participants reported that in order to physically access and use social media, they had to overcome numerous challenges, including barriers related to the use of AAC devices, limited access to mainstream technologies, and slow rates of communication. All of the participants in this study were able to overcome these barriers and took an active role in learning to use social media and integrate it into their lives. They noted the importance of the following supports to ensure their successful use of social media: technology shortcuts and supports, cyber safety measures, and education of their partners on their social media use.

Prior to this study there had been no research into the experiences with social media of adults with cerebral palsy who use AAC; however, in general terms, the results of this study are consistent with findings of other studies that have

investigated the experiences of adolescents and young adults who use AAC. These studies with younger participants also found that (a) social media was used to connect with others, most commonly within pre-established social networks of family and friends (Ellison, Steinfield, & Lampe, 2007; Lenhart & Madden, 2007; Raghavendra, Newman, Grace, & Woods, 2013; Shpigelman & Gill, 2014); (b) online interactions allowed for greater participation (Raghavendra et al., 2013); and (c) social media provided a means to overcome some of the challenges associated with face-to-face communication by alleviating time pressure (Barnfather et al., 2011; Raghavendra et al., 2013) and reducing interaction effort (Hemsley, Palmer, & Balandin, 2013; Shpigelman & Gill, 2014).

As with the present study, other researchers have also found that access to social media is not seamless for individuals who use AAC. Specifically, researchers have observed that individuals who use AAC face a range of barriers as they learn to navigate online communities (Hynan, et al., 2014; Raghavendra et al., 2013). These barriers may result from both intrinsic and extrinsic factors. Prior research suggests that the most commonly identified barriers for adolescents and young adults with complex communication needs learning to use social media are the lack of well-developed literacy skills and technology

supports (Hynan et al., 2014; Raghavendra et al., 2012). In contrast, the older participants in the present study all had well-developed language and literacy skills; they primarily highlighted intrinsic and extrinsic barriers related to access difficulties (e.g., limited motor skills), their slow rate during online synchronous communication (e.g., interactions via Google Talk²¹), and technology limitations (e.g., problems with their AAC devices, poorly designed display layouts, limited accessibility of social media sites, and difficulties connecting their AAC devices with social media sites). If there are no supports to overcome these types of intrinsic and extrinsic barriers, individuals who use AAC are at risk for exclusion from information access, full participation, and engagement in today's digital society (Baker et al., 2013). As social media use increases, so does the cost of exclusion. This is true whether that exclusion is based on technological, educational, or disability-specific barriers (Foley & Ferri, 2012).

As evidenced by this study, some individuals who use AAC have overcome intrinsic and extrinsic barriers and have successfully used social media to enhance their communication. One significant factor that may have contributed to their successful social media use was their experience using AAC. The participants all independently accessed their AAC devices and had been using AAC for many years; thus they did not have to

learn both an AAC device and the unique features of social media sites at the same time. In addition to long-time AAC use, all of the individuals who participated in this study had functional language and literacy skills. Many individuals who use AAC have limited literacy skills due to a range of intrinsic and extrinsic factors that include a lack of effective instruction (Beukelman & Mirenda, 2013). Enhancing literacy skills is essential for those who use AAC (Light & McNaughton, 2012), in order to gain access to the full gamut of technologies (e.g., email, texting, internet, social media) and participate fully in an increasingly text-based society.

Despite their success utilizing social media, all of the participants provided recommendations to enhance access to and use of social media by individuals who use AAC. Specifically, they recommended that (a) service providers support the use of social media as a form of communication; (b) policy makers recognize the necessity of access to social media and other digital communication (e.g., texting, emailing); (c) technology developers implement improvements to the general features of AAC devices, display layouts, browsers, and social media sites to facilitate seamless access, customization, and use; and (d) individuals who use AAC learn about the options provided by different social media sites and find ways to become actively involved in the development of

new technology to improve social media access. The implications of each of these recommendations are considered in the sections that follow.

Implications

Implications for Practice

Given the significant benefits of social media documented in this study, it is critical that service providers implement effective intervention to support individuals with complex communication needs in becoming effective multi-modal communicators and maximizing their competence across a wide range of media (Light & McNaughton, 2014; Shane, Blackstone, Vanderheiden, Williams, & DeRuyter, 2012). Specifically, AAC intervention must extend beyond the traditional focus on face-to-face interactions to address interactions with communication partners across a wide range of online and offline contexts as required to participate fully in educational, vocational, and social environments (e.g., social media, e-mail, blogging, cell phones; Light & McNaughton, 2014; Shane et al., 2012).

Realizing the benefits of social media is not without some cost to individuals who use AAC. With the increased demands for communication across a wide range of media come increased skill demands for individuals who use AAC. According to Light and McNaughton (2014), "...the dramatic changes in the range of AAC systems/apps,

communication technologies, and social media tools bring both benefits and challenges in terms of building, rebuilding, and sustaining the communicative competence of individuals who require AAC" (p. 10). Concerted intervention is required to ensure that individuals with complex communication needs develop the requisite linguistic, operational, social and strategic competencies to communicate not only in face-to-face interactions, but also via social media (Light & McNaughton, 2014). Communication via social media imposes increased skill demands, including for example, the development of (a) linguistic skills (appropriate vocabulary and syntax) to meet the demands of social media; (b) literacy skills to navigate the Internet successfully; (c) operational skills to access and technically operate social media sites; (d) sociolinguistic skills to determine what to communicate to whom and in what manner across a wide range of audiences on various social media sites; (e) sociorelational skills to meet the needs of diverse partners (both familiar and unfamiliar) across these sites and put them at ease; and (f) strategic competence to bypass limitations as they occur (e.g., slow rate of communication, negative social attitudes, partners who are unfamiliar with AAC; Light & McNaughton, 2014). Social media sites differ widely in the pace of interaction, privacy of messages, intended audiences, form and content of information that

can be shared (e.g., videos, images, text), and data retention policies (Bertot et al., 2012).

Interventions will need to support individuals to learn how their AAC devices interact with preferred sites, how to navigate and safely use the sites, and how to manage different media (e.g., videos, emojis²², web links, photographs) to participate. There is no doubt that individuals with complex communication needs will require concerted instruction to acquire these skills and generalize them to a wide range of social media to effectively meet diverse communication needs at home, school, or work.

Implications for Preservice and Inservice Training of Professionals

The dramatic changes in the breadth of communication media utilized in today's society have placed increased demands on not only individuals who use AAC but also service providers. Traditionally, AAC service providers have focused primarily on meeting the face-to-face and written communication needs of individuals with complex communication needs and even these needs are often not well met (Light & McNaughton, 2014). Many preservice programs for speech language pathologists, special education teachers, and occupational therapists provide only limited training in AAC and often this training is provided by faculty who are not experts in AAC. As a result, many individuals with complex

communication needs do not receive the AAC services that they require to develop communicative competence (Costigan & Light, 2010). Even when AAC services are provided to individuals with complex communication needs, social media needs are typically neglected. The expanding scope of communication poses unique challenges for preservice training. No one profession is mandated to support communication through online media. The uncertainty in regards to professional roles has resulted in minimal preservice or inservice training in this area.

The results of this study suggest that the scope of AAC practice must extend beyond face-to-face interactions and written communication, to include social media use, if individuals with complex communication needs are to become full participants in society. Preservice programs in speech language pathology, special education, occupational therapy and related disciplines must keep pace with rapid changes in communication and associated technologies in order to provide comprehensive training (Light & McNaughton, 2012). This must include issues related to social media use. Ultimately, maximizing communication outcomes for individuals who use AAC will require the effective collaboration across many disciplines.

Implications for Technology Development

In addition to skill development,

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individuals who use AAC also need access to effective social media tools. Unfortunately, the results of this study suggest that current technologies, both AAC and mainstream, pose many barriers to effective communication and social media use. When technologies are well designed, they can support efficient and effective communication (Light & McNaughton, 2014; Wilkinson, Light, & Drager, 2012); however, when technologies are poorly designed, they may impede communicative competence. The majority of AAC and social media technology lacks attention to human factors (Higginbotham, Shane, Russell, & Caves, 2007; Light & McNaughton, 2013). Furthermore, many AAC systems, mainstream technologies, and social media sites are not well integrated and do not reflect a common design that will facilitate use across platforms (DeRuyter et al., 2007). The lack of universal design features across technologies increases operational demands to effectively and efficiently access and participate in all social media environments (Light & McNaughton, 2014). Individuals who rely on AAC often require adaptations to access mainstream technologies. As a result, they may be constantly waiting for their equipment to “catch up,” leading Foley and Ferri (2012) to conclude: “The retrofit model results in outdated and inadequate technology solutions” (p. 197). Given these barriers, the benefits of social media and other new

technologies may not be fully realized for many individuals with complex communication needs (Light & McNaughton, 2013).

Researchers and developers must investigate the underlying cognitive, linguistic, sensory perceptual, and motor processing of individuals with complex communication needs and use this knowledge to drive the design of a new generation of AAC and mainstream technologies that truly reflect the needs (current and future), skills, and preferences of end users (Light & McNaughton, 2013). Currently, the development of mainstream technologies is primarily driven by the needs and preferences of the masses (Foley & Ferri, 2012) and, as a result, these technologies may not meet the skills and needs of individuals with complex communication needs. Furthermore, individuals who use AAC are typically excluded from the development process, resulting in technology that does not meet their needs and constant retrofitting of technology solutions. Including individuals who use AAC in the design process could lead to innovations and more accessible technology for all users (individuals with and without disabilities), as many of the accommodations that make the technology more accessible for individuals with disability also enhance its use for all (Foley & Ferri, 2012). A multidisciplinary approach, drawing on expertise in a wide range of domains and including individuals

who use AAC, is needed to address current barriers, impact future innovations, and advance development to create optimal access to social media and related technologies.

Implications for Policy Makers

Developing new and improved technologies is necessary, but not sufficient. It is essential that individuals with complex communication needs can procure these technologies if they are to reap the benefits and participate fully within educational, vocational, and social contexts (Williams, Krezman, & McNaughton, 2008). With the advent of the Internet, mobile technologies, and social media, communication has changed dramatically; individuals who use AAC "...have a need for, and a right to, the same range of communication options available to everyone else" (RERC on Communication Enhancement, 2011; p. 3). This includes access to social media, texting, the Internet, and speech-generating devices (McNaughton & Light, 2013). In fact, given the constraints experienced in face-to-face interactions, social media may play an even more significant role in meeting communication needs for individuals who use AAC.

Unfortunately, many funding agencies only cover the cost of dedicated speech-generating devices, which lock out access to the Internet, cell phones, and social media. These restrictive policies fail to recognize the essential role of social media

and Internet access in education, employment, and social environments and deny individuals with complex communication needs access to the full range of communication options used by individuals without disabilities. Concerted advocacy is required to change these restrictive policies and to ensure that agencies support access to the wide range of communication tools required to support inclusion and maximize participation in educational, vocational, and social contexts (Beukelman & Mirenda, 2013; Light & McNaughton, 2014).

Limitations

The results of this study make a significant contribution to the field by advancing knowledge and understanding of social media use by individuals with cerebral palsy who use AAC. However, there are several limitations that should be considered when interpreting the results. As in any focus group, only the perspectives of a small number of individuals from a particular group, at a specific point in time, were addressed. The findings may not be generalizable to the larger population of individuals with cerebral palsy who use AAC. In addition, the study does not provide information about how participants' beliefs and perspectives may evolve over an extended period of time due to changes in their individual needs, goals, and physical capabilities, as well as changes in technologies and society overall.

The study excluded individuals who were not on social media sites. Additionally, all participants were literate and had years of AAC experience. It is reasonable to assume that the views and experiences of individuals who do not use social media, are not literate, and have limited AAC experience would differ from the focus group's results. All of the participants were adults with a diagnosis of cerebral palsy, so the study does not provide information on individuals who have different diagnoses or ages. Furthermore, as with all focus groups, this study relies on self-reports, which are always filtered; the participants' reports of their experiences may or may not reflect their actual use of social media.

Future Research Directions

Based on the results of the current investigation, there are several potential directions for future research. For example, future studies should include replications of this study with other adults with cerebral palsy as well as individuals from other age ranges and disability categories. Additional questions could be added to the focus group discussion in order to investigate how individuals who use AAC also learned to use social media (e.g., who taught them, what information was necessary, how long did the learning process take?). In addition, future studies should expand to include individuals who are not independently successfully using social media, in order to

understand the potential barriers that prevent these individuals from successful and independent use.

Future research also should examine the linguistic code and sociolinguistic/socio-relational functions that individuals with and without disabilities use when engaging in social media. Extension of the current investigation to individuals without disabilities may show media preferences (text, photos, or videos), common communication topics, and types of interactions that increase communication partners' responsivity that are common or unique to online discussions. This information could lead to better interventions and more successful outcomes when introducing individuals who use AAC to social media.

Future research should also investigate the use of social media as an intervention milieu. Social media is being used in classrooms, often as a response modality or supplemental source of information. These current uses of social media could be expanded. For example, social media as an instructional milieu could provide motivating and naturalistic environments for development of literacy, vocabulary, and interpersonal communication skills.

Conclusion

Successful social media use is important in order to maximize communication for individuals who use AAC. Communication technologies continue to advance, and access to these

technologies has become increasingly important for full engagement in life (Baker et al., 2013). Social media allows users to interact and communicate rapidly, efficiently, and effectively, anywhere, anytime, with more people than ever before (Shane et al., 2012). That said, the end goal should not be to simply provide technology and access to social media, but rather to maximize communication and participation for individuals with complex communication needs (Light & McNaughton, 2013, 2014). Comprehensive AAC interventions should facilitate and support successful use of social media, and thereby provide individuals with additional avenues for communication opportunities, interactions, and greater inclusion in society.

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Endnotes

¹Phorum is an open source message board system. Additional information is available from <http://www.phorum.org/>

²Yelp is a crowd-sourced local business review and social networking site. Additional information is available from <http://www.yelp.com/>

³YouTube is a video-sharing website www.youtube.com

⁴Flickr is an image and video hosting website. <https://www.flickr.com/>

⁵Facebook is an online social networking service. Additional information is available from www.facebook.com

⁶Myspace is a social networking site that allows its users to create web pages to interact with other users. Additional information is available from <https://myspace.com/>

⁷LinkedIn is a professional social networking site. Additional information is available from <https://www.linkedin.com/>

⁸Twitter is a social networking site that allows users to send and read messages with a maximum of 140 characters. Additional information is available from <https://twitter.com/>

⁹Wikispace is a web application that allows collaborative modification, extension, or deletion of content. Additional information is available from <https://www.wikispaces.com/>

¹⁰Snapchat is a video messaging application in which users can take photos, videos, and add text or drawings, and send them to recipients. Additional information is available from <https://www.snapchat.com/>

¹¹IM (instant messaging) is a type of online chat that offers real-time text transmission on the Internet. Additional information is available from <https://www.aim.com/>

¹²Pseudonyms have been used throughout the text to protect confidentiality of the participants. The Web-based discussion did not easily support proofreading and editing as participants posted, we have made minor corrections of spelling and grammatical errors.

¹³iPhones are smartphone technology designed and marketed by Apple Inc. www.apple.com

¹⁴iPads are registered trademark of Apple Inc., Cupertino California. www.apple.com ¹⁵Trillian is a software that connects multiple instant messaging services. Additional information is available from <https://www.trillian.im/>

¹⁶YouTube video “Look Up” is a spoken word film about disconnecting from technology <https://www.youtube.com/watch?v=OKZL9HpWAmw>

¹⁷iWordQ is assistive technology writing support software. Additional information is available from <http://www.goqsoftware.com/>

¹⁸EzKeys is a software program that provides communication, computer access and environmental control. Available from <http://www.words-plus.com/>

¹⁹The Tobii I-12 is a voice output communication device. Additional information is available from Tobii ATI at <http://www.tobii.com/en/assistive-technology/north-america/>

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²⁰In the United States, Medicare covers speech-generating devices as durable medical equipment. Durable medical equipment includes items that are (a) primarily used for a medical purpose and (b) not useful to an individual in the absence of illness or injury. Manufacturers therefore, lock access functions such as Internet, e-mail, and telephone.

²¹Google Talk is an instant messaging and video chat platform. Additional information is available from <https://www.google.com/+/learnmore/hangouts/>

²²Emojis are small icons or images used to express an idea (e.g., smiley face).

²³The Pathfinder is a dedicated, voice-output communication device. Additional information is available from the Prentke Romich Company at www.prentrom.com

²⁴Skype is an application that allows for video chatting, voice calling, messaging, and file exchanging. Additional information is available from <http://www.skype.com/en/>

²⁵Speak for Yourself is an AAC application available for Apple products (e.g. iPad). Additional information is available at <http://www.speakforyourself.org/>

²⁶Proloquo2go is an AAC application available for Apple products. Additional information is available at <http://www.assistiveware.com/product/proloquo2go>

²⁷Tumblr is a microblogging website <https://www.tumblr.com/>

²⁸BYOND is an online community for creating and playing multiplayer games. Additional information is available from <http://www.beyond.com/>

²⁹PatientsLikeMe connects individuals with similar conditions to share their experiences and support each other. Additional information is available from <http://www.patientslikeme.com/>

³⁰The Eco is a communication device from the Prentke Romich Company at www.prentrom.com

³¹The Dynavox Vmax is a voice output communication device available from <http://www.dynavoxtech.com/tobii-dynavox/>

³²Pinterest allows sharing and collecting through visual bookmarks (also called boards). Additional information is available from <http://www.pinterest.com/>

³³The NOVA Chat 10 is a voice output communication device. Additional information is available from Saltillo Corporation at <http://saltillo.com/>

³⁴The Dynavox Maestro is a voice output communication device. Additional information is available from <http://www.dynavoxtech.com/tobii-dynavox/>

SOCIAL MEDIA EXPERIENCES OF INDIVIDUALS WITH CP

Table 1

Characteristics of the Participants

Participant	Matt	Will	Mark	Nicole	Chad	Pam	Kevin	Walt	Robert
Gender	Male	Male	Male	Female	Male	Female	Male	Male	Male
Age	40	45	54	39	45	23	24	58	67
Disability	CP	CP	CP	CP	CP	CP	CP	CP	CP
AAC device	Pathfinder ²³	iPad with Speak for yourself ²⁵ app	iPad with iWordQ + Proloquo2g o ²⁶ apps	Speech + Tobii I-12 device	Eco ³⁰	Dynavox Vmax ³¹	EzKeys on laptop	NOVA Chat 10 ³³	Dynavox Maestro ³⁴
Access	Direct with toe	Direct with head pointer	Direct with hand pointer	Direct with eye gaze	Direct with hand	Direct with hand	Scanning	Direct with hand	Direct with chin pointer
Preferred social media site	Facebook	Facebook	Facebook	Facebook	Facebook	Facebook	Facebook	Facebook	Facebook
Social media sites	Facebook, Google Talk, Skype ²⁴	Facebook	Facebook, Tumblr ²⁷ , LinkedIn, BYOND ²⁸ , PatientsLikeMe ²⁹	Facebook, Twitter ²¹	Facebook	Facebook, Twitter, LinkedIn, Pinterest ³²	Facebook	Facebook	Facebook, Skype
Education	College	2 years of college	Trade cert + chaplain	College	Some college	College	College	2 years of college	Associate Degree
Employed	Yes	No	Yes	Yes	No	Yes	No	Yes	Yes

Caron, J., & Light, J. (2015). "Social media has opened a world of 'Open communication.'" Experiences of adults with cerebral palsy who use augmentative and alternative communication and social media. *Augmentative and Alternative Communication*, early on-line. DOI: 10.3109/07434618.2015.1052887

Table 2

Summary of Coding Themes and Subthemes and Examples from Participants

Themes	Subthemes	Examples from participants
Advantages of social media	Connecting	I'm part of a large extended family...but we Stay in touch on Facebook.
	Feeling typical	Everyone uses social media and walks around hooked up to some device.
	Making communication easier	Calling someone is extremely difficult for me. Posting on their wall or sending them a tweet is so much easier!
	Gaining independence	I can have conversations with someone without needing a family member here to translate what I'm saying.
	Getting help	If I need advice I can post a question and most times within an hour I'll have a few answers.
Disadvantages of social media	Supporting employment	Through Facebook, I am able to promote my ministry and post Thoughts for Today.
	Cyber security threats	The only bad experience that I had was my Facebook page got hacked.
	Lacking direct contact	There is no face-to-face interaction.
	Lacking personal connection	[Surprised by the things people post] People post silly things that aren't personal.
Barriers to social media	Lacking immediate responses	You can put something on there, but you aren't going to get an immediate reaction like you would if you were discussing something in person
	Over reliance on technology	People are on their cell phones twenty-fourth seven.
	Technology barriers	My new eye gaze came with layouts that are supposed to make things easier, but there are some aspects that I don't like.
	Rate barriers	I don't get on live chat because I don't type fast.
Supports to	Physical access barriers	My beanbag tray was a small access barrier [it kept falling off my lap with my iPad].
	Accessing social media	I type something more lengthy with iWordQ, then copy and paste.

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successful use	with technology supports	I will sometimes get help with posting.
	Educating communication partners	
	Taking appropriate safety measures	I try and checkout their profile/background before I accept their [friend] request.
Recommendations about social media	Individuals who use AAC	I'm all for letting a new user play with their device to learn [social media].
	Support personnel	It would be nice to have teachers/therapists work with new users of AAC devices to show them any shortcuts that might be available.
	Technology developers	Move all delete buttons far enough away from other buttons so not to be touched/clicked on by mistake.
	Policy makers	I think we'll all agree that the Locked vs. Unlocked game we have to play is absolutely stupid. Because of social media, email and everything else, the way everyone communicates now requires an unlocked system. I can't walk or talk. The Doctors thought that I wouldn't live pass five, I'm almost 25 years old. The typewriter was my first AAC device.
Cerebral palsy experiences		
Descriptions and experiences with AAC systems		
Unrelated statements		Have a good day!

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Appendix A

Questions Posted to On-line Focus Group

1. Introduce yourself! Post three facts for others to read.
2. What are the advantages to using social media? Discuss how social media may have benefited you and why you continue to use social media sites.
3. What are some of the disadvantages to using social media? Have you had any bad experiences using social media?
4. Are there any barriers to successful use? If not now, did you face any barriers in the past that you have overcome? If so, how did you overcome them?
5. How does social media support communication and support your maintenance of friendships?
6. What features would you like to see in social media? What changes would you make to make the sites better meet your needs?
7. What suggestions do you have for support personnel/providers (e.g., teachers or therapists) in terms of social media and how it is taught or used with individuals who use AAC?
8. Do you have suggestions for ideas in terms of policy or advocacy that needs to happen in regards to communication with social media?

Appendix B

Definitions of Coding Themes

1. Advantages of social media and reasons for participating in social media: Positive results from engagement in social media including: connecting, independence, employment, networking, ease of use in comparison to other communication modes, overcoming communication barriers that are present in other modes (e.g., phone, face-to-face), maintaining/growing relationships, gaining assistance when needed, feeling typical.
2. Disadvantages of social media: Negative outcomes and experiences resulting from engagement in social media including general cyber safety concerns (identity theft, phishing scams, truthfulness, fighting) and more specific outcomes such as lack of direct contact, impersonal messages, reliance and engrossment in technology, overdependence on one tool, sites which might not be appropriate for certain conversations, lack of response.
3. Barriers to social media use: Any person, situation, action, device, application, or specific technological feature that impedes an individual's ability to efficiently use all social media sites and features. Barriers do not include recommendations for changes to these features.
4. Supports to successful use social media: Any person, organization, action, device, or feature that enables or assists an individual to access and use social media. This includes how participants currently access social media, specific access features, efficiency items, technological shortcuts, and measures that are taken by participants to ensure safe use of social media (e.g., friend request management and password protection).
5. Recommendations: Suggestions regarding ways to embrace, use, teach, and learn social media based on personal experiences and ideas. This includes recommendations to persons with cerebral palsy, support personnel, policy makers (e.g., locked vs. unlocked device issues), and technology developers.
6. Cerebral palsy experiences: Comments or questions that are related to life with cerebral palsy but not directly related to social media (e.g., "We have similar lives. I have CP too.").
7. Descriptions and experiences of present and past AAC/computer systems: Comments or questions that are related to a certain AAC device currently used or previously used, cost of the AAC device, why they used or didn't use technology in the past. This additionally includes reflections of how they were taught. Comments/questions are not directly related to how the device supports social media.
8. Unrelated statement: Comments or questions that are unrelated to cerebral palsy and not directly related to social media (e.g., "Go Nats!")