

Social Media Use and Mediated Sociality
Among Individuals with Communication Disabilities in the Digital Age

Meryl Alper (Northeastern University, USA)

Beth Haller (Towson University, USA)

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Author contact: m.alper@neu.edu

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Introduction

Throughout history, innovations in communication—be it the printed book, electricity, or the internet—have offered new opportunities for people to make social connections and express themselves with media (e.g. Marvin, 1988, Peters, 1999). While *communication studies* scholars have undertaken most research on this topic (e.g. Baym, 2010), the separate but related field of *communication sciences and disorders* is also concerned with how technologies facilitate interpersonal communication and self-expression, though primarily for the purposes of assessing and treating speech, language, and hearing impairments (Plante & Beeson, 2013). Such clinical work expressly involves communication technologies when they fall under the category of “assistive technology,” which the U.S. Assistive Technology Act (2004) defines as “any item, piece of equipment, or product system, whether acquired commercially, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.”

For people unable to or who have significant difficulty producing oral speech, assistive technologies known as augmentative and alternative communication (AAC) systems enable individuals to express their needs, wants, feelings, and preferences in ways that can be immediately understood by their conversation partners, or what speech-language pathologists refer to as “functional communication” (Kaiser & Grim, 2006). AAC *augments* other forms of communication (e.g. non-verbal gestures, non-lexical sounds such as laughter) and serves as an *alternative* to talking (Beukelman & Mirenda, 2013). Adults and children might use AAC due to

a developmental disability (e.g. autism), an injury or illness (e.g. stroke), or a progressive neurological condition (e.g. multiple sclerosis). AAC technologies span low-tech picture cards with words and symbols to high-tech computers with speech output (also known as speech-generating devices or SGDs) like the one used most famously by British physicist Stephen Hawking.

Over the past five years, smartphones, tablets, and apps that together mimic computers used exclusively or primarily as speech aids have made AAC devices on the whole dramatically more accessible, affordable, and, some argue, socially acceptable (McNaughton & Light, 2013). While laptops and personal digital assistants have been used as off-the-shelf portable AAC devices for years (Chapple, 2011), today's mobile technologies are comparatively more powerful, compact, and have a longer battery life, which is essential for communicating without worrying to stop and recharge a device.

Besides apps for AAC, mobile devices also provide other communication benefits. They offer convenient access to a wide range of popular social media apps (e.g. YouTube, Facebook, Twitter) that can connect people with disabilities to one another. Shane et al. (2012, p. 5) write, "A person may use [a speech-generating device] to have a conversation with a friend; a smartphone to send a text message to a personal care attendant across town; and post a message on Facebook to express delight with or distain [sic] for a sports franchise." Social media and networked communication technologies give individuals with significant speech and expressive language impairments opportunities to "increase, maintain, or improve" their own communication in everyday contexts, be they synchronous or asynchronous conversations, face-to-face or from a distance, and among others with or without disabilities (Caron & Light, in press; Light & McNaughton, 2014).

In this chapter, we argue that this cultural convergence between “mainstream” and “assistive” technologies (which some argue is an arbitrary distinction; see Hendren, 2013; Pullin, 2009) requires new theoretical approaches for understanding the purpose of augmentative and alternative communication devices and a reexamination of the intersections between communication studies and communication sciences. We present an integrated theorization of augmentative and alternative communication as transmission, ritual, and object. The linear “transmission model” of communication (Schramm, 1954; Shannon & Weaver, 1949; Berlo, 1960) that underpins clinical and rehabilitative perspectives on AAC is limited. We propose a more expansive notion of AAC that also embraces configurations of communication as “ritual” (Carey, 1989) and as “object” (Silverstone, Hirsch, & Morley, 1992), conceptions that originate in media and communication studies.

We advance our theorization through two case studies of communication technology use by individuals with significant communication impairments. We draw on examples from our respective qualitative fieldwork (e.g. see Alper, 2015): one, focusing on sociality through shared co-located media experiences (Alper), and the other, focusing on curation on social media platforms (Haller). To begin, the following section provides some background on the current state of the provision of multi-purpose computer-based AAC devices by individuals with communication disabilities in the U.S. (where both of the authors work and live).

Background

Third-party funding sources (e.g. Medicare, Medicaid, health insurance) are responsible for the majority of AAC device purchases in the U.S. (Seelman, 1993), with about 2,000-3,000 paid for by Medicare each year (Stockton, 2014). Insurance coverage for SGDs has undergone major shifts over the past two decades and significant upheaval in recent years. In 2001, SGDs

became a “covered benefit” under Medicare and considered “durable medical equipment,” a category that also includes wheelchairs, iron lungs, and hospital beds used at home. This expansion of coverage came with restrictions though. If the AAC device could also serve the functions of a personal computer (e.g. email, texting, web browsing), then it was not covered through Medicare.

To comply with the restrictions, device manufacturers automatically “locked” these communication features in insurance-covered SGDs. Once the AAC user owned the device, he or she could “unlock” the additional functionality, but only by paying a fee to the manufacturers (Tobii DynaVox, 2014). This system allowed for greater autonomy by AAC users, but it also inherently privileged those individuals and their families who could afford to incur the out-of-pocket costs for full communication functionality (Abbott & McBride, 2014).

A sudden revision to the SGD policy of the Centers for Medicare and Medicaid Services’ (CMS) in the February 2014 had people with communication disabilities worried about their future access to these non-speech modes of communication (Bardach, 2014). The CMS stated that they would no longer approve reimbursement for new or upgraded AAC devices on which non-AAC functions were ever possible (Center for Medicare Advocacy, 2014). The change severely restricted the ways that individuals like AAC user and researcher Michael B. Williams maintain their ties to society. Williams noted that while he had spent decades “trying to build interpersonal relationships through face-to-face communication,” human connections are increasingly remotely mediated. Said Williams,

I use the Internet every day to do research, read news, check in with friends and family via various social networking sites, video chat once a week with my daughter at college and shop online for a myriad of products and services. [...] It is vitally important these

tools and technologies are available to all persons with complex communication needs (quoted in Shane et al., 2012, p. 4).

Non-profit organization United Cerebral Palsy also weighed in on misperceptions of social media as trivial, explaining how devastating the change in CMS policy could be for people with communication disabilities: “To them, it’s not a toy; it’s a lifeline and it’s not frivolous” (quoted in Stockton, 2014, para. 25). In effect, the proposed Medicare changes would freeze AAC devices in time, out of step with technological, social, and cultural shifts of the past two decades.

Following concerted advocacy efforts from the American Speech-Language-Hearing Association, AAC users, and other stakeholders, the CMS not only rescinded the policy change in late 2014 (Duggirala, 2014), but also expanded coverage rules in July 2015 (Wilson, Kaiser, & Simpson, 2015). In a major departure, Medicare would now cover SGDs that connect to the phone and internet, allowing users to update their own software and to communicate remotely via written or voice messages (provided they pay on their own for the necessary telecommunication services).

While the change in CMS policy eliminates the need for unlocking fees, it is still restrictive in a number of ways. First, coverage is limited to computers that primarily function to generate speech and only secondarily to enable non-speech communication (Satterfield, 2015). In other words, Medicare does not cover tablets computers such as iPads for use as SGDs, though they will cover AAC apps that allow an iPad to function as an SGD. Medicare’s stated reason is that tablets “are useful in the absence of an illness or injury” and thus cannot be classified as “durable medical equipment” (Wilson, Kaiser, & Simpson, 2015). Second, the CMS policy privileges audible/verbal speech, email, text, and phone messages over other forms of communication (e.g. visual communication). Medicare will not cover “hardware or software

used to create documents and spreadsheets or play games or music, and [...] video communications or conferencing” (Wilson, Kaiser, & Simpson, 2015).

Whether or not Medicare should pay for these communication technologies is up for debate. But as we illustrate in the next section, such continued restrictions and narrow definitions of communication remain inherently out-of-touch with the ways in which individuals with significant speaking impairments engage socially with software (e.g. iTunes) and social media (e.g. Pinterest) in their daily lives, and how they do so through off-the-shelf mobile devices.

Case Studies

iTunes

When I (Meryl) first entered the home of Nash² (a 3-year-old non-speaking, non-ambulatory, upper-middle class white boy with cerebral palsy), loud funk music was playing from surround sound speakers in his living room. Rachel, the speech-language pathologist whom I was shadowing in her AAC device consultations with families, explained that Nash’s mom, Taylor, was a musician, and that she and her husband, Todd, had been playing music to Nash since he was a baby. As Taylor fed Nash through his feeding tube, she bobbed to the music with him on her lap. Todd commented that Nash was more adult than kid-like in his musical preferences, noting, “He’s not typical—I mean, we listen to Miles Davis together.” In terms of atypicality, Todd was not referring to Nash’s physical development, which caused him to use a wheelchair and require round-the-clock attendance, but rather his musical tastes.

Nash loved music so much so that his iPad (purchased out-of-pocket by his parents) not only had the AAC app Proloquo2Go installed, but also held a vast iTunes library of mp3s.

² Names of children with communication disabilities, names of their parents and therapists, and the names of adult individuals with aphasia have been changed to protect their privacy.

During another visit I made to Nash's house, Rachel and Taylor reorganized a stored set of phrases in the Proloquo2Go app that allowed Nash to request specific musical artists (e.g. Bill Withers, Aretha Franklin) from iTunes. Though Nash could not use Proloquo2Go to directly trigger the playing of music in iTunes, he could use the app to ask another person to select the song of his choice. The songs that Nash chose were an important way for him to speak on his own behalf. Nash's daily communication with Proloquo2Go and his frequent expression through his iTunes music catalog were intertwined on his iPad and his family's shared iTunes account.

This overlap was also a source of tension between Nash's family and his school. After an initial home visit, my second encounter with Taylor was a month later at a local assistive technology conference. During a Q&A session with parents of children using AAC devices, Taylor raised her hand and asked the panelists for some advice. She said that she wanted to upgrade Nash's iPad from a nearly-obsolete first-generation one to a third-generation one, but wondered about the pros and cons of asking the school to provide one for Nash as part of his Individualized Education Plan (IEP) versus maintaining family ownership. She wanted to ensure that Nash retained access to his music, but was concerned that there might be issues with having two iTunes accounts (home and school) for downloading media and apps on the same device. In addition, Taylor said, "His music has swear words on it," not something that school would likely consider appropriate. All of the parents on the panel agreed that Taylor should go ahead and make the purchase. "The ideal is if you own it," said one mother, but "it has to be written into the IEP."

Using the social, cultural, and economic resources at her disposal (a privilege that not all parents of children with disabilities share), Taylor was able to advocate on Nash's behalf for him to use the family-owned iPad in school. A few months later, towards the end of another

consultation visit that Rachel and I made to Nash and his family, Taylor asked Nash to choose an activity he'd like to do. He raised his right arm to indicate, "yes," when Taylor suggested, "have a dance party," a favorite family routine. Seeing Todd working on a computer out of the corner of her eye, Taylor called him over. He playfully evaded until he got up from his office chair. "See, Nash, the power of communication!" Taylor said to her son, with a wink towards Rachel and I.

Todd selected a song from the iPod hooked up to the living room speakers, and "Jump in the Line (Shake, Senora)" by Harry Belafonte burst from the walls. He scooped Nash up into his arms, tossed him into the air with dangling feet, and twirled his dance partner around. Nash grinned big and smiled even wider when Todd stomped in time with the calypso beat. Taylor, turning to Rachel and I, remarked that she was glad that Nash had a way to ask for dance parties and ready access to music for dancing. "He's learning that if you ask for what you want," Taylor said, "all of a sudden you can do something awesome." Nash's affinity for music was deeply linked to his identity and his familial bonds. Beyond the Proloquo2Go AAC app, the personally curated digital library of music on his iPad and on the family iTunes account allowed him to express himself and expanded his communication options with his social partners.

Pinterest

Assisting those with the communication disability aphasia now involves much new technology, as well as social media. Aphasia is rarely discussed but actually quite prevalent as a communication disability that comes from a stroke or traumatic brain injury. "Nationally, more than one million Americans are living with aphasia," said Denise McCall, program director for the Snyder Center for Aphasia Life Enhancement (SCALE) in Baltimore. "Aphasia is more prevalent than Parkinson's disease, cerebral palsy, or muscular dystrophy, yet public surveys

show that only one in 100 people know about aphasia” (see McCall, 2013a; Code et al., 2001). SCALE is one of eight independent aphasia centers in the U.S. (Elman, 2011) that addresses the ongoing needs for people with aphasia who are no longer eligible for rehabilitation, but struggle to engage with daily life because of their communication impairments.

I (Beth) observed programs at SCALE multiple times to see their innovative use of social media for people with aphasia. McCall said that because most people with aphasia are over 50-years-old, they are looking for ways to continue to communicate with their younger family members, who sometimes don't know how to maintain a relationship when verbal speech is gone or impaired (B. Haller, personal communication, November 25, 2014). In addition, individuals with aphasia need to advocate for themselves in new ways, she said. Besides courses in photography, art, and gardening, SCALE offers classes on how to use Pinterest, Skype, Facebook, Twitter, and YouTube with the intention to “empower individuals with aphasia to advocate and educate” (McCall, 2013b).

Founded in 2008, Pinterest is a web and mobile application for the creation and sharing of visual bookmarks, or “pins,” on personalized Pinterest pages, or “boards.” The way Pinterest is used is one of the more innovative ways SCALE supports communication instruction for individuals with aphasia. McCall, who is a speech-language pathologist, said Pinterest is particularly useful for people with aphasia because some studies show they can process realistic pictures much better than icons or drawings (Rose et al., 2011). Photos on Pinterest stimulate the brains of individuals with aphasia for conversation prompts, and the individuals are in control of what prompts they use and how they decide to use the photos to communicate. This is in contrast with a medical professional imposing his or her ideas on the individuals with aphasia. In addition, Pinterest allows individuals with aphasia to organize their thoughts around themes,

which enhances their ability to build communication structures by themselves, McCall explained (B. Haller, personal communication, November 25, 2014).

Pinterest does not get much attention from researchers as a social media platform compared to Facebook and Twitter (Chang, Kumar, Gilbert, & Terveen, 2014), but it is still used by many people, especially women. The Pew Research Center's Internet Project reports that the percentage of online adults using Pinterest increased from 15% in 2012 to 21% in 2013 (Duggan & Smith, 2013). It has become a gendered social media space, with women four times more likely to use Pinterest than men (Duggan & Smith, 2013). Demographically, Pinterest is also used much more by white online adults, with 18% using the site, compared to 8% of blacks and 10% of Latinos (Delo, 2013). However, these national statistics do not take regional demographics into account. In the city of Baltimore, for example, about 63% of residents are black or African American (U.S. Census, 2010).

On one visit to SCALE, I brought several international visitors who were interested in how social media can be used to empower people with disabilities, as other researchers have also examined (e.g. Shpigelman & Gill, 2014; Dobbs, 2009). Individuals with aphasia introduced themselves in various ways, some using audio prompts on an iPad and several using Pinterest that was projected on a screen. Myra's Pinterest page was an in-depth introduction to her interests. Myra is an over-50 black stroke survivor; the stroke affected her vocal cords, which no longer allow her to make sound. Myra used her Pinterest page to introduce herself to me and the international visitors through her curated images and captions. Of her 30 pins, the first 10 were about SCALE activities, her family, her dog, but the other 20 pins were about her love of Westerns, both films and TV shows, with several pins about the actor Rory Calhoun, who starred in film Westerns in the 1950s and 1960s. What was so powerful about her Pinterest introduction

was that if we had interacted with Myra verbally, it is unlikely that we would have learned about her interest in Westerns. In a verbal conversation, we might have only learned the information in the first 10 pins. This image-based curation on Pinterest of what interested Myra gave everyone meeting her in-depth information and a glimpse into her real passions.

SCALE has its own group Pinterest page, with 29 individuals with aphasia using the social media platform. The number of images pinned range from 1 to 82, with three women, all black, having pinned the most. Other SCALE members revealed their fandom for Michelle Obama or love of TV game shows and stylish women's hats. McCall said some SCALE members use Pinterest for communication in the community, such as pointing to a picture of food they want order in a restaurant (B. Haller, personal communication, November 25, 2014). Other SCALE members have bonded with their spouses by collaborating on Pinterest pages about shared interests or past travel. McCall explained that many times that their families also have newfound respect for the individuals with aphasia when they illustrate their proficiency with a range of social media apps and then use them to communicate (B. Haller, personal communication, November 25, 2014).

Pinterest is also uniquely useful for individuals with aphasia, McCall said, because, in addition to a communication disability, someone who has had a stroke may have an impairment in one or both of his or her hands, making typing difficult (B. Haller, personal communication, November 25, 2014). Because Pinterest is image-based and typing captions for pictures is optional, it is an excellent platform for some stroke survivors. Government programs, such as Medicare, and many speech-language pathologists are clearly unaware of how the curation function available on social media like Pinterest serves to empower people with communication

disabilities, as well as how their curation of images is a form of communication with their family members, friends, and community.

Discussion

The examples of iTunes and Pinterest as personally meaningful communication technologies for individuals with significant speech impairments suggest the need for broader interpretations of what constitutes “functional communication” and what determined Medicare coverage. While the early focus of AAC technology in the 1970s and 1980s was on synchronous face-to-face interactions (Shane et al., 2012), interpersonal communication has broadened in subsequent decades to include more networked and remote forms (Baym, Zhang, & Lin, 2004). Conversely, all communication technologies used by individuals with and without disabilities might be rethought as existing on a spectrum between augmentation and alternatives to oral speech (Alper, in press), reflecting the idea that all technologies are “assistive” in some manner (Hendren, 2013).

Government policies about assistive technology have long had problems that lead to discrimination against people with disabilities. Seelman (2013), for example, argues for more equitable policies because they will lead to empowerment, independence, and community inclusion for disabled people. Medicare’s insistence that communication technologies like those used by Nash and Myra to produce digital or synthetic speech should only secondarily be capable of that function is grounded in a medical model of disability. This view inaccurately frames disability as something to be cured in the individual (Linton, 1998), leading to the conclusion that communication technologies should remedy breakdowns in communication by fixing the “broken” person with impaired speech. Engelke (2013) contends that the very term

“AAC user” inherently places more emphasis on the speaker and their sending of unambiguous messages, and less so on the listener and their role in the social co-construction of meaning.

Recent critical work exploring the intersection of communication studies and communication sciences illustrates how what are seen as “natural” forms of communication and expression are socially constructed (Axel, 2006; Sterne, 2003; Mills, 2009). With respect to AAC, clinicians generally guide individuals with significant speech impairments in how to use AAC devices to meet the daily communication needs that they would otherwise have met through “natural” communication methods (i.e. oral speech) (Beukelman, 1991). By this definition, even though social media is embedded in all aspects of daily life, it is considered “unnatural.”

At the core of the debate over what counts as legitimate mediated communication by individuals with communication disabilities are three different theories of communication, each with their own complex origins and legacies that is beyond the scope of this chapter. First, restricting communication technology use by individuals with communication disabilities to “functional” purposes reflects the transmission or “sender-receiver” model of communication. This model, developed at Bell Labs by Shannon and Weaver (1949) in their work on telephony, has had a far-reaching influence not only on speech-language pathology, but also on cybernetics, linguistics, and modern communication theory (Axel, 2006). This model characterizes a “successful” communication act as one in which a message is transferred from point A to point B through channel C with its singular meaning intact. From this perspective, language and information are quantifiable in terms of amount and frequency, which speech-language pathologists can then measure.

However, as communication theorist James Carey (1989) pointed out in his landmark essay, “A Cultural Approach to Communication,” the transmission model of communication is limited in that it does not take into account how social and cultural dynamics shape the meaning of messages, or what Carey termed a “ritual view of communication” (p. 15). Drawing on the work of anthropologist Clifford Geertz (1973), Carey wrote (1989, p. 23), “communication is a symbolic process whereby reality is produced, maintained, repaired, and transformed.” Quantitative measures of communication do not fully capture whether or not a communicative act was a success. For example, the number of Facebook “likes” on a post cannot tell us what a Facebook like signifies to each person who clicked on the like icon. From this perspective, all media that augment and provide an alternative to oral speech—from AAC software to social networking sites—are in some way made meaningful through this interpretive process. As long as AAC is seen primarily as a tool for the transparent transmission of messages, there is a missed opportunity to support more creative, multimodal expressions among individuals with communication disabilities through media and communication technologies (Pullin, 2009).

In addition to the transmission and ritual view of communication, focusing respectively on effects and meanings, a third theory—domestication (Silverstone, Hirsch, & Morley, 1992)—also underlies part of the conceptual split over AAC devices. Domestication theory posits that since media and communication technologies are material objects with a physical presence, they develop their own “biographies” as they accompany individuals throughout their lives. People with communication disabilities grow attached (or come to loathe) particular media platforms and the specific AAC devices they use (whether they are owned, rented, or borrowed). The proposed changes to Medicare policies do not take into account that mobile technologies for communication are themselves expressive and are not interchangeable with traditional SGDs.

Conclusion

Adults and children with significant speech and expressive language impairments—across race, ethnicity, class, gender, sexuality, and nationality—are adapting a variety of social media and new media platforms as ways to communicate in innovative ways, from creating an iTunes playlist to curating an array of photos on Pinterest. Their transformational use of new communication technologies and social media educates society about broader definitions of what human communication might truly be. Assistive technology policies denying access or making access to social media very difficult for people with significant speech impairments restricts their personal relationships and societal participation, and in turn, also denies society the opportunity to learn from those who engage in communication in unique ways. People with communication disabilities can be leaders in showing how new media could be used in a myriad of unexpected ways that end up benefitting society broadly, not just individuals with significant speech impairments. Validating the countless ways adults and children with communication disabilities use media and technology socially everyday requires an integrated theorization of augmentative and alternative communication that takes into account understandings of communication as transmission, ritual, and object.

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