

Chapter 13 Digital & Social Media: Using New Tools to Support the EHDI System

K. Todd Houston, PhD, CCC-SLP, LSLS Cert. AVT

ithin each state's Early Hearing Detection and Intervention (EHDI) system, multiple agencies work to ensure that communication and information sharing remains clear and consistent. EHDI coordinators have reported that communication is a strength of their program, and maintaining relationships with key stakeholders is essential to their success (Bradham & Houston, 2011). While consistent contact among vital stakeholders is often the intended goal, many program administrators find it difficult to maintain. Too often, administrators fall into comfortable-but isolating-"professional silos," leaving the lines of communication in tattered fragments.

The typical administrator tries to reach out to their agency's stakeholders through traditional means, such as a static website, phone calls, or email. However, these methods often prove to be time-consuming and inefficient. Physicians, program administrators and their agencies, service providers, and most importantly parents/caregivers are turning to digital media and online social networking to establish direct ways of connecting, communicating, and collaborating. Simply relaying information is no longer considered adequate. Basic information should be provided only as a starting point that facilitates deeper engagement and prolonged interaction. It is imperative for EHDI and Part C coordinators to establish a digital presence for their programs. As Howard Luks, MD, states, "At its heart, digital media is about people. It is about relationships. It is about communication. A social media presence is about educating, engaging and growing your audience, improving outcomes, and compliance" (Luks, 2011).

While consistent contact among vital stakeholders is often the intended goal, many program administrators find it difficult to maintain.





Hospitals, medical centers, and physician practices are greatly expanding their use of social media and related technology to connect with their patients. Today's evolving social networks have
taken the shape of communities for those
who are separated by time and distance.about
cons
on m
nine communities to solve problems.Increasingly, people are turning to their
online communities to solve problems.or m
online
conc
conc
conc
data and American Life Project (2014), 56%becc
people
peopleof respondents have seen an online grouppeoplepeople

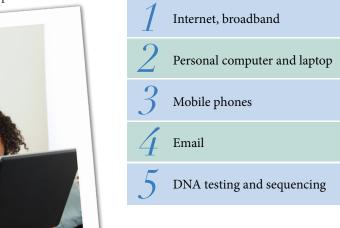
of respondents have seen an online group come together to help an individual member or to solve a problem that affects many within the community. People with similar challenges from different parts of the world are uniting to provide mutual support, networking, and information sharing.

A Digital Transformation of Healthcare

Americans are increasingly using the Internet to engage in a wide range of activities from social networking to interacting with professional service providers to more mundane activities, such as shopping or watching the latest viral video. In fact, according to the Pew Research Center's Internet & American Life Project, 84% of all U.S. adults use the Internet, and more importantly, 59% seek out health information while online (Pew Research Center, 2014). Often these adults seek peerto-peer interactions to gain more insight into a particular disease, medical condition, or treatment. Fox (2012) reports that 34% of Internet users have read someone else's commentary or experience

about health or medical issues; 24% have consulted online reviews of particular drugs or medical treatments; and 18% have gone online to find others who might have health concerns similar to theirs. Seeking healthcare information through online sources is becoming a routine behavior for many people. Technology continues to shape how individuals interact with their healthcare providers. Whether using a laptop, tablet computer, or mobile device, such as a smartphone, consumers are leveraging this new level of connectivity to interact with their healthcare providers to receive a range of treatments and interventions. With the recent COVID-19 pandemic, a great deal of connectivity has been mandated by concerns regarding transmission of the virus through individual close physical proximity or hazards of group gatherings.

Hospitals, medical centers, and physician practices are greatly expanding their use of social media and related technology to connect with their patients. While some physicians are embracing this new level of connectivity, others argue that healthcare providers are just starting to comprehend the potential that these technologies, when appropriately utilized, can do to improve patient outcomes. In his book, *The Creative Destruction of Medicine: How the Digital Revolution Will Create Better Health Care* (Topol, 2012), Dr. Eric Topol identifies the biggest innovations of the past 30 years:



Topol recognizes that the typical smartphone now incorporates the first four of these innovations, and he predicts that in time, the fifth—DNA testing and



Photo courtesy of Octicon A/S



Social media represents those channels or outlets that allow users to make connections. sequencing—will be added to mobile devices. Topol states, "These extraordinary accomplishments . . . have set up a profound digital disruption of medicine. Until now, we did not have the digital infrastructure to even contemplate such a sea change in medicine, and until now, the digital revolution has barely intersected the medical world. But the emergence of powerful tools to digitize human beings with full support of such infrastructure creates an unparalleled opportunity to inevitably and forever change the face of how healthcare is delivered" (Topol, 2012, p. 5).

The evolution of these technologies will continue to impact healthcare and how diagnostic and treatment services are delivered across disciplines, including speech-language pathology, audiology, and the EHDI and Part C systems. Pandemic precautions have only served to dramatically alter service delivery in favor of technology rather than close physical contact.

Defining Digital & Social Media

Often the terms digital media and social media are used interchangeably. However, purists would argue that the term digital refers to the medium in which information is conveyed (i.e., Internet, online). Social media represents those channels or outlets that allow users to make connections. Defining it more specifically, Kaplan and Haenlein (2010) refer to social media as the use of web-based and mobile technologies (e.g., smartphones, tablet computers) to turn communication into an interactive dialogue that allows for the creation and exchange of usergenerated content. To clarify the various forms of social media, the researchers also developed a classification scheme to describe each (Kaplan & Haenlein, 2010):

- Collaborative projects (e.g., Wikipedia)
- Blogs and microblogs (e.g., WordPress, Twitter, Tumblr)
- Content communities (e.g., YouTube, Vimeo, Flickr, Pinterest, Instagram, Vine Snapchat)

- Social networking sites (e.g., Facebook, LinkedIn, Google+)
- Virtual game worlds (e.g., World of Worldcraft)
- Virtual social worlds (e.g., Second Life)

Other categories include social news (e.g., Digg, Reddit) and bookmarking sites (e.g., Stumbleupon, Delicious). Therefore, a well-defined online social presence will incorporate several of these instruments.

WhoIsUsingSocialMedia?

Duggan and Smith (2013) found that 73% of adult Internet users use a social networking site like Facebook or LinkedIn—up from 65% in 2011. They found that Facebook was the most popular—with 71% of adults regularly using this social network, which was an increase from 65% in 2012. For all five of the "major" social networking sites (i.e., Facebook, Twitter, LinkedIn, Instagram, and Pinterest), membership has risen. In the same report, Duggan and Smith found:

- A majority of users on both Facebook and Instagram check their profiles on a daily basis.
- Sixty-three percent of Facebook users report checking their profile at least once a day, with 40% checking multiple times per day.
- Fifty-seven percent of users check their Instagram once a day, with 35% checking multiple times per day.
- Facebook remains the largest and most popular network, with more than 1.23 billion users worldwide.
- For users who only use one social network, 84% of the time that network is Facebook.
- Twenty-two percent of Internet users surveyed have not adopted any of the five major platforms, but half of Internet users who do not use Facebook live with someone who does.

In recent years, the growth of social networking sites has been meteoric. In contrast, just 8% of Internet users—or 5% of all adults—reported joining or being a member of these sites in 2005. By



comparison, of the "daily" online activities that were surveyed, only email (which 61% of Internet users access on a typical day) and search engines (which 59% use on a typical day) are used more frequently than social networking tools.

According to Madden and Zickuhr (2011), social networking sites are most popular with women and young adults under the age of 30. Young women, aged 18-29, are the most frequent users of social networking—with nearly 90% of those who are online accessing the sites and 69% visiting social networking sites on a daily basis. For men who are online, 60% use social networking sites, and 38% visit those sites on a daily basis. Eight out of ten Internet users ages 18-29 use social networking sites (83%), compared with 7 out of 10 (70%) 30 to 49 year olds, half of 50 to 64 year olds (51%), and a third of those age 65 and older (33%). The aging community has been among the slowest to adapt to new trends in social media, but recent research has indicated that seniors are the fastest-growing demographic. In 2014, 59% of seniors reported using the Internet, which is a 6% increase from 2012 and a 26% jump from 2008 (Reading Eagle, 2014).

There are no significant differences in use of social networking sites based on race and ethnicity, household income, education level, or whether the Internet user lives in an urban, suburban, or rural area. These results underscore the fact that Internet use and social networking are on the rise across all demographics, especially those who may be seeking services or other support from both EHDI and Part C programs.

Social Media & Social Networking: We're All Living Socially!

While some Internet companies that provide social networking opportunities or other web-based services may no longer be popular (e.g., Myspace), even the casual observer can no longer ignore the explosion of social media. It is shaping the ways people shop, socialize, and learn about the world around them. To highlight the scope and reach of social media, Smith (2017) made several observations, as shown in *Table 1*. Consequently, while certainly not limited to the U.S., the use of social media continues to have a profound effect on nearly every aspect of American culture.

Social Media in Healthcare: A Shift in Communication

Through social media, individuals have the opportunity to connect with others who have shared experiences or similar interests. Once a diagnosis is suspected or confirmed, individuals often conduct web searches to gather additional information, visit the website of a noted medical facility or practitioner, or watch related videos that have been posted on a contentsharing website. Increasingly, people are turning to their online social networks for information, support, and other resources when a health-related crisis emerges. According to a recent study (National Research Corporation [NRC], 2011), 1 in 5 Americans use social media websites as a source of healthcare information. NRC surveyed nearly 23,000 consumers and found that 94% of respondents indicated they had used Facebook to gather information about health-related issues. Some 32% of the respondents listed YouTube, and 18% had used Twitter.

Within the same study (NRC, 2011), researchers found that when asked about social media's influence, 25% of respondents said it was "very likely" or "likely" to influence their healthcare decisions. When asked about their level of trust in social media, 32% said "very high" or "high," and only 7.5% said "very low." Half of the respondents (50%) preferred their hospital or medical provider's websites as a primary source of online health information, but 14% preferred an integrated approach of websites and social media.

Through social media, individuals have the opportunity to connect with others who have shared experiences or similar interests.

Table 1 Observations on the Scope & Reach of Social Media

One of every five people on earth is on Facebook. With more than 2 billion users, it could be considered the most populated country (if it had geographical constraints) in the world.
Facebook adds six new profiles every second—meaning 500,000 new profiles are created every day.

More than 1 billion people access Facebook through their mobile devices (e.g., smartphone, tablet computer).

More than 5 million websites have integrated with Facebook.

Approximately 250 billion photos have been uploaded to Facebook, which equates to 350 million photos per day.

YouTube—the video sharing site—has 1.5 billion unique users who generate 300 hours of video uploaded every minute. Users can navigate the site in 76 different languages, covering 95% of the Internet population.

Snapchat—the instant photo and video sharing app—and its 178 million active users generate 8 billion video views a day.

People upload 3,000 images to Flickr—the photo sharing website—every minute. It now contains more than 5 billion images.

Twitter handles nearly 500 million tweets per day from 328 million active accounts.

J LinkedIn—a networking site focused on professionals—has more than 500 million individual members and 3 million companies worldwide.

Google+—a more recently launched social networking site—has more than 111 million users.

Recent research has examined and demonstrated the influence social networks can have on healthcare decisions. Recent research has examined and demonstrated the influence social networks can have on healthcare decisions. Centola (2011) studied 1,528 participants who had anonymous online profiles coupled with a series of healthrelated topics. Participants were matched to groups of other "health buddies" who shared the same interests or diagnoses. Periodically, participants received email updates about the activities of their health buddies. The participants were placed into one of two distinct social networks one with fewer overlapping interests or another that contained larger clusters of people with closer relationships. The groups were then asked to register online at a health forum website that sought ratings of consumer health resources. Centola (2011) found that 54% of the people within the clustered network (i.e., individuals with stronger ties to each other) registered for the health forum on the website, and the rate of participation was four times faster. Only 15% of participants with one friend in the forum returned to it. However, more than 30% of participants with two friends returned,



Access to digital health can provide new and exciting communication opportunities for individuals who are deaf or hard of hearing (D/HH) and their families, including an increased ability to find information about the services available in their community. and 40% of participants with three friends made repeated visits to the online forum. Thus, peer-to-peer recommendations from a shared community or network provided more influence, and those recommendations were more successful at shaping behavior.

The Rise of Digital Health

Chin and Ravendra (2014) defined digital health as the "convergence of the digital and genetics revolutions with health and healthcare," but it goes far beyond that. Digital health includes several specific categories of healthcare, including:

- Health Informatics (i.e., the intersection between health, technology, and business).
- eHealth (i.e., electronic medical records and decision support systems).
- mHealth (i.e., use of mobile technologies ranging from text message appointment reminders to healthcare smartphone apps).
- Telehealth (i.e., use of telecommunication technology to support interactive healthcare).
- Social media (i.e., disease tracking and surveillance).
- Big Data (i.e., capturing all the information about a patient in order to give them a more complete view of their access to care coordination and reimbursement).
- Wearable technology (fitness and other health monitors that can track and maintain the health of wearers).

Access to digital health can provide new and exciting communication opportunities for individuals who are deaf or hard of hearing (D/HH) and their families, including an increased ability to find information about the services available in their community. As digital health becomes increasingly integrated into the standards of care in healthcare, EHDI and Part C program administrators must remain cognizant that digital tools are significantly more effective than static technologies in reaching the families that they wish to serve. Likewise, parents of newly identified children who are D/HH may turn to these same digital tools as a means of finding information; interacting with other families who are already receiving services; and seeking out qualified professionals, programs, and services that meet the needs of their children and family.

Wearable Technology & the Quantified Self

Emerging in the realm of digital health is wearable technology. Forbes (2014) calls wearables "the new new digital health" and claims that "health wearables are growing up." These are devices worn by the user in the form of watches, bands, bracelets, glasses, and other similar technology. They gather information about the wearer's physical state and provide data useful to measure improvement or progress, depending on the individual's health condition or goals.

Data obtained from wearables is creating the *quantified self*, which is defined as "a movement to incorporate technology into data acquisition on aspects of a person's daily life in terms of inputs, states, and performance" (Forbes, 2014). Driven by the human tendency towards self-improvement, devices such as Spire (which provides feedback on focus and calmness) and Evoke (whose sensors collect information on brain activity and heart rate variability) are providing the user with data to help quantify their quality of life (Forbes, 2014).

Wearables debuted at Silicon Valley's 2014 Health 2.0 event and seemed rather far-fetched at the time. The application of these technologies to children with hearing aids and cochlear implants has become quite evident. For example, wearables can monitor the listening environment and measure if a child shows increased stress or anxiety in a specific setting. Other wearables may measure a child's language use, the number of words spoken to the child, and how many conversational turns The Internet of Things and wearable technology movements are gaining rapid momentum and will change the way people perceive the world and themselves. were taken between the child and parent or caregiver. This data has the potential of providing greater insight into the child's developmental and communication outcomes in "real-world" settings.

Wearables of the Future & the Internet of Things

The content experts consulted for the Pew Internet Project (2014) "agree that the expanding networking of everything and everyone-the growth of the Internet of Things and embedded and wearable devices-will have widespread and beneficial effects by 2025." Service models-from early intervention to a range of healthcare or treatment approachesand the technological world will combine in various ways, because "wearable, connected devices will become embedded more and more in our bodies, more like implants" (Forbes, 2014). Surgery will be required to adopt the newest technology. Medical devices, such as hearing aids and cochlear implants, will be connected to and controlled by central processing devices that also control communication, the flow of information, and incoming data. The ability to track how a child is performing with their technology will be done through this interconnectivity of devices. That data could be monitored by



Photo courtesy of Octicon A/S

the early interventionist and/or program coordinator.

As technology implanted in the body becomes more and more common, the wearable will normalize the medically implanted device and make cochlear implants and auditory brain-stem implants seem commonplace. As Forbes (2014) mentions, "We will see today's connected devices become smaller and smaller and slowly merge into the part of the body from where the particular sense related to that device operates." The Internet of Things and wearable technology movements are gaining rapid momentum and will change the way people perceive the world and themselves. This shift will affect children with sensory impairment, such as hearing loss, with dramatic improvements in assistive technology.

Mobile Health (mHealth)

Perhaps one of the most accessible forms of digital health will be mHealth via the use of smartphones. Many Americans are using their smartphones to access information about healthcare and healthcare providers. According to Pai (2013), 95 million Americans are using mobile phones as tools to find health information. This is a rise from 75 million in 2012. Seven out of ten doctors report having a patient who takes some sort of consistent health measurement with their mobile phones. Thirty-one percent of doctors say they make prescription and/or treatment decisions from their smartphones, and 74% of doctors use their smartphones for professional purposes—up from 68% in 2012. Pennic (2012) reported that physicians spend an average of 11 hours per week online for professional purposes. Thirty-nine percent of physicians communicate online with their patients via email, secure messaging, or video conferencing. Pennic (2012) also found that 80% of Internet users will look online for health information, 20% will search for health-related content on their mobile devices, and 23% will use social media to follow the health experiences of their friends.



Using social media tools has become an effective way to expand reach; foster engagement; and increase access to credible, science-based health messages. One of the barriers to a wider adoption of mHealth is skepticism. Delotte (2013) reported there are several aspects of digital health that led consumers to be wary. Twenty-two percent of their survey respondents report that mobile health apps are not likely to be reliable and accurate, and 31% believe that mobile health apps are likely to have potential errors. Likewise, 31% did not see mHealth apps as something to manage serious illness but as something only appropriate for fitness and wellness. Beyond reliability and accuracy of services provided from health apps, 35% of responders fear that mobile apps are not secure enough to protect important health records and private information.

Beyond these concerns, there are still many individuals interested in the rise of mHealth. Thirteen percent of responders say they have used mobile health technology to transmit personal health information, and 46% of responders say they are interested in doing so in the future. Thirty-six percent have no concerns about paying medical bills online. The majority of responders reported they would be comfortable using mobile technology to:

- Learn more about treatment options.
- Choose what is right for them.
- Address health concerns with their healthcare provider via email or text.
- Consult with a medical professional using a video Internet connection.

The results of this survey confirm that consumers are interested in moving towards more widely acceptable mobile health but will need to be assured of the accuracy, reliability, and security of using mobile devices to access private health information. These trends continue to influence and shape the future of service delivery in healthcare, which also impacts services provided to families of young children who are D/HH. As families experience the increasing availability of digital health services, they will also begin to expect such services to be available from more providers. EHDI and Part C administrators, early interventionists, and other practitioners serving young children who are D/HH and their families should take advantage of these new opportunities to create an interactive digital health service plan.

Opportunities for EHDI & Part C Programs

According to the Centers for Disease Control and Prevention (CDC, 2011, p. 1), "Using social media tools has become an effective way to expand reach; foster engagement; and increase access to credible, sciencebased health messages." For EHDI and Part C programs, establishing and maintaining a social media presence is now a necessity. Administrators must be willing to position the program where, when, and how consumers wish to be engaged, typically through a variety of social media (e.g., Facebook, Twitter, YouTube). When a stakeholder-physician, speech-language pathologist, pediatric audiologist, early interventionist, or parent/caregiver-wishes to interact with the program, that individual should be able to find the program through their preferred social media or network. A static, template-driven website is no longer adequate to meet the needs of today's EHDI and Part C stakeholders.

A range of service providers and other professionals within the EHDI and Part C systems are beginning to embrace social media. For example, the American Speech-Language-Hearing Association (ASHA) has a Facebook page where speech-language pathologists, audiologists, students, and researchers are able to:

- Post information related to speech, language, or hearing issues.
- View related videos with a link to YouTube.
- Learn about upcoming events.
- Seek professional opportunities through a career center.

Similarly, audiologists and speechlanguage pathologists are using Twitter to provide links to online content, search for information, and build social networks by "following" other individuals, organizations, or businesses to receive updates. Professionals have Evidence continues to show that parents are using the Internet, social networking sites, and social media to access information on a range of health-related topics, identify resources, participate in support groups, make family-tofamily connections, and advocate for continued services. developed groups through other social networking sites, such as LinkedIn. These groups are both profession-related (e.g., speech-language-hearing professionals) or set up to support networking and collaboration around a specific interest, such as telemedicine/telepractice, early intervention, or spoken language acquisition in children who are D/HH (e.g., 6 Sound-Off, Telepractice in Speech-Language Pathology).

Physicians are increasingly turning to social media and building an online presence to engage with their patients. Modahl, Tompsett, and Moorhead (2011) reported that 90% of physicians use at least one social media site for personal use, and over 65% use the sites for professional purposes. Haupt (2011) found that more than 1,300 doctors have registered with TwitterDoctor.net-a database of physicians who tweet (i.e., send messages of 140 characters or less through Twitter). Physicians are finding it easier to connect with patients outside their offices. Social media provides another channel to provide patients additional information about various diagnoses, treatment options, and medical procedures, as well as to answer questions. As Thomas Lee, MD, states, "It's an electronic way of extending the conversation. It creates a vibrant sense of community and wonderful back-andforth dialogue" (Haupt, 2011).

Evidence continues to show that parents are using the Internet, social networking sites, and social media to access information on a range of health-related topics, identify resources, participate in support groups, make family-to-family connections, and advocate for continued services (Khoo, Bolt, Babl, Jury, & Goldman, 2008; Knapp, Madden, Wang, Sloyer, & Shenkman, 2011; Plantin & Daneback, 2009; Porter & Edirippulige, 2007; Skinner & Schaffer, 2006; Trotter, 2008). Parents are seeking information and support through their online engagement. Porter and Edirippulige (2007) found that parents of children who are D/HH use the Internet to search for unbiased information about hearing loss and communication options, intervention

and educational choices, hearing technology, service providers, and avenues for parent and family-to-family support. Through a comprehensive social media presence, EHDI and Part C programs have the opportunity to engage and connect families—as well as other stakeholders—to a range of information, resources, and online communities.

Social Media: Where to Start

As with most significant undertakings, establishing an efficient social media presence requires careful planning. Administrators need to work with staff members and primary stakeholders to evaluate their needs, examine available resources, and craft a comprehensive social media strategy that can be incorporated into the larger program or agency communication plan. Ultimately, the social media strategy, by its nature, must be flexible and allow people to conveniently participate and access information in numerous ways whenever they wish to do so.

The CDC (2011) has developed comprehensive resources on how to develop and design a social media strategy, including a planning form that is adapted and summarized in *Table 2*. EHDI and Part C coordinators can use this outline to develop a social media strategy. By carefully planning the social media strategy and measuring the outcomes, EHDI and Part C programs will remain well positioned to meet the online needs of their stakeholders.

A Practical Use of Digital Media to Improve Outcomes in EHDI

As more and more EHDI and Part C programs begin to develop and utilize a comprehensive social media strategy, creative uses will emerge that will most likely have a positive impact on children who are D/HH, their families, and the professionals who serve them.

Table 2 How to Develop a Social Media Strategy

 Identify	Determine	
Target Audience(s)	Your Objective	Goal Integration
 Describe the stakeholders the programs are attempting to reach. For example, those individuals could be: Parents/caregivers. Extended family members, such as grandparents. Families who speak English as a second language (i.e., ESL). Nurses and hearing screening technicians. Physicians (i.e., family practitioners, pediatricians, otolaryngologists). Service providers (i.e., early interventionists, speech-language pathologists, audiologists, teachers of the deaf). Family support organizations (i.e., local chapters of Hands & Voices and the Alexander Graham Bell Association for the Deaf & Hard of Hearing [AG Bell]). Other state agencies, researchers, and university partners. 	 What does the program want to achieve through social media? For example, does the program wish to: Decrease loss to follow-up after newborn hearing screening? Improve family participation in early intervention service delivery? Increase direct communication among the program's service providers? Connect families to other families with children with hearing loss to facilitate family-to-family support? Foster greater collaboration between state agencies? As objectives are finalized, use SMART (i.e., Specific, Measurable, Achievable, Realistic, Time-bound) goals to maintain clarity of focus. 	 Administrators should: Describe how the program's social media objectives support the organization's mission and/or overall communication plan. Detail how it supports other online or offline components. For example, how does the social media outreach fit into the larger communication plan for the program or agency? How well is the social media plan integrated with existing online tools, such as the program's website or existing social media efforts? Some programs may use some social media tools, such as a Facebook page or Twitter account. However, if a social media plan was never developed, those tools may not be maintained or effectively utilized.
Define Audience		Resources

Communication Needs

Message Development

Stakeholders will access the program through various social media outlets, at different times of the day/night, and for various purposes. Surveying the program's stakeholders to determine their communication needs will aid in deciding how to proceed. What are the key messages based on the target audiences and the identified objectives? These messages should speak directly to the target audience, be relatively short and to the point, and encourage a desired response or action. For example, to encourage parents of young children who are D/HH to keep hearing aids on their infant or toddler, a message could be, "A child is never too young to hear a parent's voice."

Resources and Capacity

The next step is to determine program resources and overall capacity to support a social media strategy. Administrators must determine who will be responsible for implementation and how much time can be devoted to creating content, updating information or messaging, maintaining the various social media outlets/accounts, and providing general support to these efforts.

NATIONAL CENTER FOR HEARING ASSESSMENT & MANAGEMENT

Table 2 (continued)

Identify Social Media Tools

Define Activities

Deciding which social media tools to employ should be based on the needs of the target audiences and the program's stakeholders. To establish a social media presence, a Facebook page may be the first place to start. Links to online resources, guidelines, program policies, schedules of notable meetings or events, and videos of parents discussing their experiences can easily be added. The page can also function as a place where parents can post questions for staff members or connect with other parents who have similar experiences. Once the Facebook page is established, the program may wish to add other social media tools, such as a YouTube channel, to post informative videos about child development, communication options, hearing technology, or other topics related to either EHDI or Part C. A Twitter account can be used to deliver information to stakeholders quickly and to post links to other information online. As the needs of the program and its stakeholders evolve, additional social media tools should be added to meet those objectives.

Once the social media tools have been selected, defining how they will be used is critical. Following a management plan to ensure that all of the activities are carefully planned and coordinated is the key to success. Consistent communication with the program's stakeholders will allow close monitoring of their communication needs. The social media strategy needs to be flexible enough to address new or shifting demands. New technology and social media tools will emerge, and continued adaptations will be required.

Define Success for Evaluation

For EHDI and Part C programs, a successful social media presence will be reflected in outcomes that can be documented. If one objective is to use social media to improve communication with parents and increase compliance with follow-up audiological diagnostic appointments, that is a measurable outcome. In this example, success can be defined as the number of children receiving audiological evaluations in a timely manner. Hopefully, after the implementation of a coordinated social media plan, those numbers will increase. For each objective established for social media outreach, determining what success looks like will be essential.

Identify Key Partners and Their Roles and Responsibilities

One of the biggest challenges to maintaining a social media presence is the generation of new, relevant content. Static content, which is typically stored on a website, is important as reference material. Stakeholders should always be directed there, as needed. However, what about a new policy that has just been released? This information should be sent quickly through email, as well as posted on the Facebook page. A staff member should send a tweet with a link to the online policy, alerting all of the program's followers on Twitter about the posting. All of this should occur as quickly as possible. To achieve this level of efficiency, the process must be finely tuned. Who will generate the content (i.e., the policy) and then upload it to the website? Who will post it to the Facebook page and monitor comments on the wall? Who will monitor the tweets that will be generated? To be successful, all of these activities must be carefully coordinated. In this example, the tweet cannot be sent until the policy is written and posted. Establishing partnerships among key staff members or with external stakeholders to assist with the development of content, posting of new information, and monitoring of postings or comments is critical to the program's overall success.



Table 2 (continued)

Evaluate

As mentioned above, the CDC (2011) has developed a comprehensive social media guide for healthcare providers that includes recommendations for social media evaluation. The suggested approach calls for identifying the program's

inputs, outputs, and outcomes. For example, inputs could be the number of messages generated by staff or other content partners. Outputs are the products generated through social media. These could be the number of tweets sent and then retweeted through Twitter. Outputs could be the number of page views, friends obtained, or followers. They could also be the number of posts to a Facebook page, and then the number of subsequent "shares" or comments that are generated. There are

several online websites that can assist with capturing and generating these analytics. Outcomes, as mentioned previously, are the long-term behaviors or changes that are most desired.



text4baby supports moms by providing accurate, text-length health information and resources in a format that is personal and timely, using a channel she knows and uses. As strategies are developed, it will be important to research current uses of both digital and social media. One such approach involves the use of text messaging with mobile phones. It is now estimated that nearly 100% of the U.S. population will own or have access to mobile phones with texting capabilities (Terry, 2008). Teenagers and young adults are using email and phone calls less and less and preferring text messaging as their primary mode of communication (Luks, 2011).

An innovative use of mobile and social media is the website text4baby (www. text4baby.org), which can serve as a model for both EHDI and Part C programs. As described on the text4baby website, "Despite decades of public health outreach and education, more than 500,000 babies each year are born prematurely, and an

estimated 28,000 children in the U.S. die before their first birthday. Many factors cause these negative outcomes, including healthcare access, poverty, and negative health behaviors. Research supports the fact that increasing knowledge around health can help people stay healthier."

The website goes on to explain the organization's mission, "To help more pregnant women and new moms get information about caring for their health and giving their babies the best possible start in life. The National Healthy Mothers, Healthy Babies Coalition (NMHB) launched text4baby-the first free health text messaging service in the U.S. text4baby supports moms by providing accurate, textlength health information and resources in a format that is personal and timely, using a channel she knows and uses."

text4baby requires mothers to register by simply sending a text from their mobile phone. Mothers send a text to a specific phone number and are prompted to enter the child's name, due date/birthday, and zip code. Once registered, the mother receives free messages with health tips about pregnancy and caring for the newborn.

Because text messaging is increasingly being utilized by hospitals and other healthcare providers (Terry, 2008), a similar system could be launched for EHDI and Part C programs to expand the programs' reach and improve stakeholder responsiveness. For example, parents of a child who has not passed a newborn hearing screening in the hospital could be asked to register their mobile phone for direct texts and updates. Texts about subsequent hearing screening or appointments for follow-up audiological evaluations could be sent. After the date of the audiological evaluation had passed, a follow-up text could be sent for the parent(s) to notify the hospital, the EHDI program, and possibly Part C about those results. Similar texts could be sent to the audiologist to ensure that lines of communication remain open. If the child was diagnosed as being D/HH, a text message could serve as a reminder to the audiologist to make appropriate referrals to early intervention/Part C. Once Part C has received the referral, another text message could be sent back to the state EHDI program for tracking and monitoring purposes.

Generating text messages can be a costeffective step to raise overall program efficiency. Several companies provide automated texting services that are usually initiated through a software solution in conjunction with existing hospital telecommunication systems. While this is a contrived scenario, a text messaging system supporting EHDI and Part C is just one tool that may reduce loss to follow-up and help to ensure that children who are D/HH and their families receive all of the services necessary for successful outcomes.

Future Directions

The world is changing. New technologies allow people to connect, communicate, and collaborate in exciting new ways. From trivial matters, such as shopping for a new sweater, to reading the menu of the newest restaurant, to searching for more serious topics like "childhood hearing loss," to finally joining an online social network, the use of the Internet and social media continues to evolve. How information or online networks are accessed is changing as devices become faster, smaller, and evermore mobile, such as tablet computers and smartphones. Many hospitals, healthcare providers, and related organizations are starting to utilize social media and digital health strategies to connect with their patients and foster deeper engagement and improved outcomes. For most EHDI and Part C programs, social media is an untapped tool that is yet to be fully realized. With careful planning and coordination, programs have the opportunity to design, coordinate, and maintain social media outreach that has the potential to expand service delivery and ensure improved results for children who are D/HH and their families. When that happens, we all can tweet about those successes and discuss them on Facebook!

The world is changing. New technologies allow people to connect, communicate, and collaborate in exciting new ways.



References

- Anderson, J., & Rainie, L. (2014). The Internet of things will thrive by 2025. *Pew Research Center*. Retrieved from http://www.pewinternet.org/2014/05/14/internet-of-things/
- Bradham, T. S., & Houston, K. T. (2011). Future directions for EHDI programs: Recommendations from a strategic analysis. *The Volta Review*, 111(2), 281-288.
- Centers for Disease Control and Prevention. (2011). *The health communicator's social media toolkit*. Available at http://socialmedia/tools/guidelines/pdf/ SocialMediaToolkit_BM.pdf
- Centola, D. (2011). The spread of behavior in an online social network experiment. *Science*, *329*(5996), 1191-1197.

Chin, C., & Ravendra, M. (2014, February 14). *The new era of digital health*. Available at cyhealthcommunications.wordpress.com/2014/02/14/the-new-era-of-digital-health/

- Fox, S. (2012, November 8). *Mobile health 2012*. Retrieved from http://www.pewinternet. org/2012/11/08/mobile-health-2012/
- Haupt, A. (2011). How doctors are using social media to connect with patients. U.S. News and World Report—Health. Available at https://health.usnews.com/health-news/most-connected-hospitals/articles/2011/11/21/how-doctors-are-using-social-media-to-connect-with-patients
- Hixon, T. (2014). The new, new digital-health-wearable products. *Forbes*. Retrieved from http://www.forbes.com/sites/toddhixon/2014/09/30/the-new-new-digital-health-wearable-things/
- Kaplan, A. M., & Haenlein, M. (2010). Users of the world, unite! The challenges and opportunities of social media. *Business Horizons*, *53*, 59-68.
- Khoo, K., Bolt, P., Babl, F. E., Jury, S., & Goldman, R. D. (2008). Health information seeking by parents in the Internet age. *Journal of Pediatrics and Child Health*, 44, 419-423.
- Knapp, C., Madden, V., Wang, H., Sloyer, P., & Shenkman, E. (2011). Internet use and eHealth literacy of low-income parents whose children have special healthcare needs. *Journal of Medical Internet Research*, 13(3), e75.
- Luks, H. (2011). *Establishing a digital media presence*. Available at http://socialmedia. mayoclinic.org/
- Madden, M., & Zickuhr, K. (2011). 65% of online adults use social networking sites. *Pew Internet & American Life Project*. Available at http://pewinternet.org/Reports/2011/ Social-Networking-Sites.aspx
- Modahl, M., Tompsett, L., & Moorhead, T. (2011). *Doctors, patients, & social media. QuantiaMD CareContinuum Alliance.* Available at www.quantiamd.com/q-qcp/ DoctorsPatientSocialMedia.pdf
- National Research Corporation. (2011). *Ticker survey: 1 in 5 Americans use social media for healthcare information*. Available at http://hcmg.nationalresearch.com/public/News.aspx?ID=9
- Pai, A. (2013, November 26). *51 digital health metrics in 2013*. Available at http://mobihealthnews.com/27638/51-digital-health-metrics-in-2013/4/
- Parulkar, I. (2014). The Internet of everything—harnessing the full potential of Internet of things. *The Economic Times*. Retrieved from http://articles.economictimes.indiatimes. com/2014-09-19/news/54109072_1_internet-devices-wider-adoption
- Plantin, L., & Daneback, K. (2009). Parenthood, information, and support on the Internet. A literature review of research on parents and professionals online. *BMC Family Practice*, 10, 34. Available at http://www.biomedcentral.com/1471-2296/10/34
- Porter, A., & Edirippulige, S. (2007). Parents of deaf children seeking hearing lossrelated information on the Internet: The Australian experience. *Journal of Deaf Studies and Deaf Education*, *12*(4), 518-529.
- Reading Eagle. (2014). *Social media keep retirees connected*. Retrieved from http:// readingeagle.com/ap/article/social-media-keep-retirees-connected

NATIONAL CENTER FOR HEARING ASSESSMENT & MANAGEMENT

- Skinner, D., & Schaffer, R. (2006). Families and genetic diagnoses in the genomic and Internet age. *Infants & Young Children, 19*(1), 16-24.
- Smith, A. (2010, August 11). *Home broadband 2010*. Available at pewinternet.org/~/ media//Files/Reports/2010/Home broadband 2010.pdf
- Smith, K. (2019, Jan 2). Marketing: 122 amazing social media statistics and facts. Available at https://www.brandwatch.com/blog/amazing-social-media-statistics-and-facts-for-2016/
- Terry, M. (2008). Text messaging in healthcare: The elephant knocking at the door. *Telemedicine and eHealth*, *14*(6), 520-524.
- Topol, E. (2012). *The creative destruction of medicine: How the digital revolution will create better health care.* New York, NY: Basic Books.
- Trotter, M. I. (2008). Patients' use of Internet for health-related matters: A study of Internet usage in 2000 and 2006. *Health Informatics Journal*, *14*(3), 175-181.



A RESOURCE GUIDE FOR EARLY HEARING DETECTION & INTERVENTION