



HHS Public Access

Author manuscript

Assist Technol Outcomes Benefits. Author manuscript; available in PMC 2023 May 11.

Published in final edited form as:

Assist Technol Outcomes Benefits. 2022 ; 16(2): 104–110.

“Include Me”: Implementing Inclusive and Accessible Communication in Public Health

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Abstract

To ensure access to health communication, attention must be paid to the needs of all audiences. As scientists working in a highly technical organization, we often focus more on methods and findings without giving the same thought to how we convey messages and the communication needs of specific audiences. In this essay, we outline how we learned a great deal about communications during the planning and execution of a Public Health Grand Rounds (PHGR). This PHGR gave us a chance to pause and consider what was most important: our public health messages, making them relevant and understandable, ensuring they were informative and actionable, and maximizing accessible outlets and methods for disseminating our messages.

Keywords

inclusion; intellectual disability; accessible communications; disabilities

“Include me, include me in my community. I need to feel like I belong in my community. I need to feel like I belong in the organization. I need to feel like I belong in that doctor’s office. I’m the patient. I’m the one that people need to talk to, not my mom, not my dad, not my provider, not a supporter.”

– Liz Weintraub, Association of University Centers on Disabilities senior advocacy specialist and person with an intellectual disability

According to the American Association on Intellectual and Developmental Disabilities (AAIDD), intellectual disability (ID) is defined as “a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which originates before the age of 18” (Schalock et al, 2010). Although current data on health outcomes are very limited for people with ID (van Schrojenstein Lantman-de Valk, 2005), data that exist indicate that, compared to the general population, people with ID are more likely

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to experience a wide variety of health problems (Gleason et al., 2021; Tarasoff, 2020; van Schroyenstain Lantman-de Valk, 2000), experience challenges to accessing quality health care (Evenhuis, 2001; Sakellariou, 2017), have increased morbidity (Kamalakaran, 2021; Koyama, 2022; Reichard, 2019; Traci, 2002) related to higher rates of co-occurring conditions, and have higher mortality rates (Morgan, 2001). As noted in the 2005 Surgeon General's Call to Action to Improve the Health and Wellness of Persons with Disabilities (USDHHS, 2005), people with all types of disabilities can achieve optimal health and wellness; however, they need health information and tools delivered to them in a way that is relevant, understandable, and actionable.

The general effective communication requirements under Title II of the Americans with Disabilities Act (ADA) and Section 508 of the Rehabilitation Act help ensure that communications for people with disabilities are as effective (defined as clear and understandable) as communications for people without disabilities (FCC, 2020; USDOJ, 2007). This is meant to provide equal access to information for people of all abilities through "auxiliary aids and services." Such aids and services include qualified interpreters, audio recordings, large print materials, and real-time captioning; however, "generally, the requirement to provide an auxiliary aid or service is triggered when a person with a disability requests it" (USDOJ, 2007). Instead of waiting for such a request, organizations can be proactive in their communication approaches to ensure that people of all abilities can access and understand important information. Accessible communication not only benefits people with disabilities, but can help organizations ensure that all people can access, understand, and act upon information that is provided. In this way, by being proactive, accessible communication becomes part of the organization's culture, rather than a one-time event or an exception to the rule.

The value of health communication is diminished if the intended audience cannot access or understand the messages. Health communications best practice stresses that the information being communicated meet the needs of the audience and be presented in a way that is actionable (USDHHS, 2016). In October 2019, CDC's Division of Human Development and Disability (DHDD) hosted a Public Health Grand Rounds (PHGR), Addressing Gaps in Health Care for Individuals with Intellectual Disabilities (<https://www.cdc.gov/grand-rounds/pp/2019/20191015-intellectual-disabilities.html>). The proactive communication efforts undertaken by this PHGR helped raise awareness of the need for a public health focus on ID, and mobilized CDC and partner organizations to set a model for full, accessible health communication for people of all abilities.

Choosing Relevant Topics and Engaging Speakers

DHDD strives to promote health equity for individuals of all abilities. The PHGR provided exploration of a public health topic in depth, as well as a discussion of opportunities and challenges. This opportunity required that critical public health information be communicated to a wide audience and fully include people with ID. The DHDD staff engaged in this effort, beginning with careful consideration of which panel topics could represent the most current and salient issues to our audiences. Selected topics highlighted efforts to improve health outcomes for people with ID, how data can be a useful tool

to help communities and healthcare professionals reach these outcomes, and about the benefits of health programs for children and adults with intellectual disabilities. We also critically assessed which speakers could provide this information in an engaging and thought-provoking way.

To continue implementing essential health communication strategies and to draw and increase the appeal to a wide-ranging audience, the DHDD planning team worked to include a variety of personal and professional experiences and perspectives on the panel. Speakers were disability senior advocacy specialist, Ms. Liz Weintraub; professor and researcher, Dr. Susan Havercamp; chairman of a national organization that serves individuals with disabilities, Dr. Tim Shriver; and Developmental-Behavioral Pediatrician and DHDD director, Dr. Georgina Peacock. This PHGR was the first to feature a panel member with ID; as she is a senior advocacy specialist, individual disability advocate, and person with ID, Ms. Liz Weintraub's personal perspective was extremely valuable. Ms. Weintraub's participation educated the broader audience, and challenged the PHGR planning committee and speakers to ensure that presentation slides and information could be accessed and understood by the widest audience possible.

Maximizing Accessibility

Like many professional presentations given at conferences or meetings, PHGR panel presentations are usually very technical and can be difficult for a lay audience to understand; even more so for people with ID who might need simple terminology to be able to fully grasp the content. To address this communications challenge, CDC worked with the panelists and organizations who hosted the speakers to ensure that their presentations used plain language (USGPO, 2010) and accompanying easy-read notes. Easy-read notes utilized a few words and images to describe the main message for each slide. The easy-read notes were posted to the PHGR site for public access.

Historically, PHGRs used American Sign Language (ASL) interpreters only when requested by individual attendees in advance. For this PHGR, we hired an interpreter without waiting to receive a request. We placed the interpreter alongside the podium during the presentations; thus, the interpreter could be seen by online viewers who needed ASL. In addition, Communication Access Real-time Translation (CART), also known as live captioning, was made available for in-room and online audiences. Having PHGR accessible orally, in writing, and in ASL, both in the room and for online audiences, helped ensure wide participation and reduce disparities in access and understanding. Finally, because the floor of the meeting space was not on a slant, and the ASL interpreter was standing at the front of the room, adequate spacing was created between the rows of chairs to allow participants to view the interpreter and speakers. This physical accessibility of the meeting space also helped ensure that people using wheelchairs or other mobility support could easily navigate the room and see the speakers.

Including Members of the Audience

A primary component of PHGR is “Beyond the Data” (BTD). BTD is a video segment that provides an opportunity for discussion about public health application of PHGR and, as the name implies, it focuses beyond just what the data say and more on what the content means for public health and clinical practice. For this PHGR, we believed that having a person with ID host the segment would provide valuable insight; therefore, Ms. Liz Weintraub was invited to present on the panel as well as host BTD. This was the first time BTD was hosted by an individual with the lived experience of the impact of programs addressing health care gaps for people with ID. We believe this helped make the information more relevant to many members of our audience.

Ensuring Compliance

Another important and legally-required communication step in planning a federal government-sponsored program is to ensure that all associated materials used before, during, and after the event are 508 compliant, which enables users and viewers of all abilities to have full access to web and electronic content. This compliance is required by Section 508 of the Rehabilitation Act of 1973, amended and included in 1998 (FCC, 2020). We worked with communication specialists trained in 508 compliance to ensure that all PHGR promotional and marketing materials, speaker slides, and communications items were 508 compliant.

Engaging National, State, and Local Partners

To both increase awareness among PHGR attendees of local resources and provide an opportunity for ID-serving partner organizations to showcase the availability of their resources, DHDD hosted a first-time health information fair before and after the PHGR. The fair provided a way for local partners to communicate in person, answer questions, and clarify information shared. Many PHGR attendees were not familiar with these organizations, so this health information fair also helped raise visibility of the breadth of work that these partner organizations lead and how their efforts align with the work of CDC.

We also worked with national disability partners to hold a meeting immediately following the PHGR to discuss practical application of the points raised in the PHGR. Often times, such large meetings end without a tangible follow-up. By having a meeting following the PHGR, we ensured that ideas were still fresh from the session. This allowed for a fruitful discussion with clear next steps for how organizations could collaborate in the future. Virtual remote conferencing technology was used to maximize the number of organizations that could participate. More than 40 partner organizations shared their ideas for how their groups could collectively help advance programmatic work and research related to ID.

Lessons Learned

PHGR was attended by 251 in-person participants, 46 via Internet Protocol Television (IPTV), and 971 via live webcast. Attendees represented three countries, 43 U.S. states, and the District of Columbia. The DHDD planning team learned a great deal about how to

succeed in implementing fully inclusive public health meetings and sessions. Some of the main lessons included:

- It is essential to include people with disabilities for events at every phase, from conceptualizing, planning, implementing, and evaluating all programs, to ensure that inclusion is achieved.
- Working with partner organizations and colleagues who can model inclusive program practices can help with peer-to-peer education of other groups and people who may not be familiar with disability inclusion.
- When systems are not universally designed, there is always an opportunity for public health officials to question whether inclusive practices are being used and influence whether more can be done.

The communications aspects of this PHGR serve as prime examples of how public health organizations can be proactive and intentional about communicating data, science, research, and programs to ensure that they are accessible to all people. By using inclusive tools and technologies, engaging partners, and including people with ID to contribute their insights and lived experiences to the conversation, this PHGR enabled all people to access and understand relevant, actionable information. These efforts can be sustained over time and become a model for how public health organizations, and all organizations, can optimize their tools to reduce disparities and achieve full communication equity.

DECLARATIONS

The findings and conclusions in this report are those of the author(s) and does not necessarily represent the official position of the Centers for Disease Control and Prevention or ATIA. Development of these materials was supported in part by a grant from the CDC Foundation, using funding provided by its donors. The materials were created by the Center for Inclusive Design & Innovation (CIDI), Georgia Tech. The CDC Foundation and Centers for Disease Control and Prevention (CDC) provided subject matter expertise and approved the content. The use of the names of private entities, products, or enterprises is for identification purposes only and does not imply CDC Foundation or CDC endorsement.

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