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Voices from the Field

Building an Effective Model to Disseminate Accessible COVID-19 Guidance

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ABSTRACT

In July 2020, the CDC Foundation partnered with the Center for Inclusive Design and Innovation (CIDI) at the Georgia Institute of Technology to deliver critical COVID-19 guidance to people with disabilities, their families, and caregivers. The project made information from the Centers for Disease Control and Prevention (CDC) accessible for audiences with vision and hearing disabilities and extremely low literacy levels. The dissemination challenge was communicating the availability of the products in digital and embossed Braille, American Sign Language videos, and simplified text products to the intended users. Working with the American Association on Health and Disability, a project partner, CIDI constructed a network of organizations to disseminate information about project services through virtual speaking appearances, webinars, and social media messaging to organizations that reach the intended audiences. The accessible products are distributed to the target audiences through a website and key partnerships for the physical distribution of embossed braille products.

Keywords: accessible information, COVID-19, dissemination model, braille, American Sign Language, simplified text

BUILDING AN EFFECTIVE MODEL TO DISSEMINATE ACCESSIBLE COVID-19 GUIDANCE

The purpose of the Accessible Materials and Culturally Relevant Messages for Individuals with Disabilities Project, funded by the CDC Foundation in 2020 and conducted by the Center for Inclusive Design and Innovation (CIDI) at Georgia Tech, is to deliver messages of critical health importance about COVID-19 to people with disabilities, their families, and caregivers. The project makes guidance from the Centers for Disease Control and Prevention (CDC) accessible through alternate formats for individuals who are blind or have low vision, who are deaf or hard of hearing, or who have cognitive disabilities requiring text at extremely low reading levels.

The largest audience of people with disabilities is composed of people with mobility impairments, both temporary and permanent. The range of mobility disabilities manifests in many ways, and assistive technologies (AT) have been instrumental in facilitating the acquisition of information in many circumstances. The information accessibility needs of individuals with physical and sensory disabilities are addressed with products in American Sign Language (ASL), braille, audio formats, and accessible documents. Led by researchers from the Center for Literacy and Disability Studies, Department of Allied Health Sciences at the University of North Carolina at Chapel Hill (UNC), in partnership with a CIDI team, the team pioneered the innovative development of a new level of text simplification for individuals with extremely limited literacy.

The primary objective of this dissemination model is to identify effective channels for the delivery of CDC COVID-19 guidance in alternative formats to the entire community of individuals with disabilities and their support circles. Secondary, and parallel to, the delivery of the healthcare messages, is the delivery of information about the project and improved strategies to meet the healthcare information needs of people with disabilities.

The network for dissemination of COVID-19 messages is designed to inform and to create awareness of protective guidance, to engage people with disabilities in strategies to protect themselves and others from the virus, and to encourage active participation of people with disabilities in efforts to prevent and/or reduce the spread of COVID-19.

Dissemination of products and messages relies primarily on information and communications technologies (ICT) but encompasses other formats to reach target audiences. In using ICT at its core, the plan recognizes that disabilities are greater among rural and tribal populations, and that broadband access is less available. The plan employs diverse partners in a multi-tiered network to optimize reach to as many people with disabilities as possible.

TARGET AUDIENCES AND RELEVANCE

The target audiences for this article are users of alternative media, families, caregivers, organizations that support and advocate for them, healthcare providers, and providers of healthcare guidance.

Relevance: This article, in describing the project dissemination model, highlights the need for a readily available network to communicate protective information to people with disabilities and their caregivers in emergencies.

LITERATURE REVIEW

Most dissemination planning focuses on sharing research results for incorporation into practice. Methods and sources center primarily on communicating to academic or clinical peers. This project seeks to realize its objective by communicating with the intermediaries (disability and advocacy organizations) who disseminate messages, not to researchers, but to populations with disabilities that need access to critical healthcare guidance. The project has the added challenges of providing (1) an accessible portal for end users to view or download information products, (2) an accessible portal for individuals to request products in embossed braille, and (3) an effective physical distribution strategy for embossed braille products. The model is one of academic dissemination combined with marketing promotion and distribution for information and products.

One useful source of guidance for dissemination planning was the Quick-Start Guide to Dissemination for Practice-Based Research Networks (AHRQ, 2014). Training for dissemination frameworks at CDC (Elsberry & Mirambeau, 2015) and the Dissemination and Engagement Planning Checklist (CDC, 2014) were helpful. A primer on the use of web metrics (Schierle, 2019) provided guidance on activities to evaluate the success of internet dissemination.

Segmentation of Target Audiences

Disability is a major factor in healthcare, education, and employment. The overall incidence of disability in the US is 13.2% (Statistica, 2019), but 41.4% of individuals over 65 have one or more disabilities. Overall, mobility issues are most common, followed by cognitive, hearing, and vision disabilities.

The target audiences for the COVID-19 products are individuals who have limited mobility or are blind, deaf, or have limited literacy skills resulting from a variety of factors. Specific new products address the impact of CDC guidance on individuals with limited mobility or one of the sensory disabilities. Some individuals have a combination of these disabilities. Mobility issues may limit physical access to health guidance or limit the ability to comply with the protective aspects of the guidance. The age of onset of the disability, the current age of the person, and other age-related conditions or health factors may exacerbate some disabilities or influence the preferred format for messages or the preferred method for seeking or receiving messages. Therefore, some product formats may be used by multiple audiences.

Mobility and Physical Related Disabilities

Mobility impairments affect 13.7% of the population (CDC, 2021). Covering a wide range of functional disabilities, mobility impairment may be temporary or permanent, the result of conditions at birth, or caused by illness or accident. Included in the category are amputation, arthritis, back disorders, cerebral palsy, and neuromuscular disorders. While people over 65 are most likely to have a mobility impairment, it can occur at any age. Most significantly, it can affect physical functioning at home, school, and in the workplace. It can impact physical access with loss of function in specific body parts and may result in compromised independence.

Assistive technology (AT) is available to mitigate some effects of mobility impairment. Access to compensating AT may be compromised or delayed by the individual's insurance coverage, or the lack thereof. Accessible communications, especially speech-driven digital communication, are critical to those with disabilities affecting their hands and arms. Those same disabilities may necessitate caregiver services for activities of daily living such as dressing, eating, and bathing.

Cognitive Disabilities

Cognitive disabilities affect 4.5% of the population and include intellectual disabilities (CDC, 2021). One specific interest of this project is the community of individuals functioning at literacy levels as low as 3rd grade and below. In addition to intellectual disability, issues related to reading may include effects of stroke or traumatic brain injury (TBI). The reading levels addressed for this population were far below those targeted by the Plain Language initiative and required the development of new guidelines and tools for text simplification grounded in evidence-based research (the previously-referenced initiative led by researchers from UNC in partnership with CIDI/Georgia Tech).

Deaf and Hearing-Related Disabilities

The overall prevalence of hearing loss among the public is about 3.5% (CDC, 2021). About 14% of adults (over 18) have some degree of hearing loss, with the greatest impact in the population of adults ages 60–69 (CDC). American Sign Language (ASL) is used by approximately 500,000 people in the U.S. and Canada. It is not a translation of English, but a language with its own syntax. ASL is a dynamic language, with users introducing or adopting new signs as needed. Variations of ASL are used in communities around the world (e.g., Puerto Rican ASL), but may vary significantly based on the dominant language and culture.

Blindness and Vision-Related Disabilities

Blindness or low vision affect 3.8 million people in the US population, or about 2.4% overall (CDC, 2021). The proportion rises sharply to 6.6% in those over 65 due to various conditions including cataracts, diabetic retinopathy, open angle glaucoma, and age-related macular degeneration. Only 10% of blind individuals read braille, the tactile writing system invented in the 19th century (NFB, 2019). This is attributable to the shortage of braille teachers. Many individuals who use braille have access to digital content that can be downloaded to refreshable braille displays of various sizes. Those with vision loss who do not use braille often use text-to-speech assistive technology called screen readers to access digital content.

Caregivers and Supporting Networks

Many individuals with disabilities rely on a supporting network of family, friends, caregivers, or service providers. This makes information about COVID-19 equally important to the network of supporting individuals because all need to be familiar with guidance appropriate for the individual with the disability and those assisting the individual.

Members of the support network often share living quarters or visit the living quarters of individuals with disabilities. The high usage of personal caregivers is a critical factor in limiting the transmission of COVID-19.

Product Differentiation and Dissemination

Appropriate methods and channels of dissemination were devised for the alternative formats into which the COVID-19 guidance was translated. The translation of materials and messages into three primary formats (ASL, braille, and simplified text) was consistent with the highest quality standards for each format.

American Sign Language Videos for Deaf Individuals

Using CDC guidance documents, the team developed ASL scripts for video production that recognize the culture of the Deaf community and the unique aspects of the language. The modified process to improve quality included preparation of an English ASL script (following ASL syntax) that also served as captions for the guidance videos, followed by preparation of a gloss script for the ASL signs prepared by a certified ASL interpreter for use by the CDC interpreters. Script preparation included use of standardized signs (as agreed upon in the community of users) and a reduced reading level because many deaf individuals read below standard grade levels.

Braille and Other Formats for Blind and Low Vision Individuals

CIDI's premiere braille production group is a member of the Braille Authority of North America (BANA) and includes Library of Congress certified braille transcriptionists. Embossed braille was distributed to users through existing providers and directly by special request through the project website. Accessible portable document format (PDF) files for use with refreshable braille displays or text-to-speech assistive technology for individuals, schools, government agencies, and employers are available on the website, and so are accessible Word files.

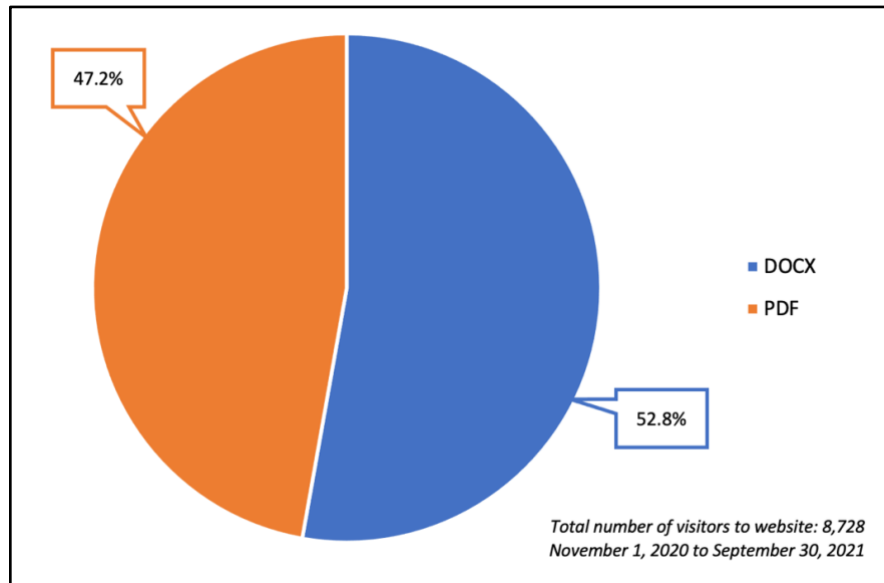
Simplified Text Products for Ease of Reading

As noted earlier, a significant number of Americans have minimal literacy skills (below 3rd grade level). This factor is a risk to health outcomes. The project partnership of UNC researchers and CIDI staff collaborated to address this challenge. Although Plain Language is a means of simplifying text, it is not sufficient to ensure comprehension for persons with written language comprehension skills below the 6th grade level. The UNC researchers drafted research-based guidelines for minimizing text complexity for individuals who understand written language at beginning levels (i.e., below 3rd grade level). CIDI staff (trainee users) developed initial products to communicate CDC guidance to test the Guidelines for Minimizing the Complexity of Text in developing materials for this audience segment.

Word and PDF Files for Accessibility

Documents in Microsoft Word and PDF files provide access to information across the disability spectrum. Many individuals use assistive technology (with computers, tablets, and mobile phones) to support access to and use of the internet and applications for work, learning, and recreation. As noted earlier, individuals who are blind or have low vision and use braille displays are among the users of these file formats. So are people who use screen reader software and text-to-speech applications. These include people with mobility disorders who have no use, or limited use, of their arms or hands; people with learning disabilities; people who are auditory learners; and others.

Figure 1: Accessible Document Downloads



As indicated in the graphic, usage of Word and PDF files was almost evenly split.

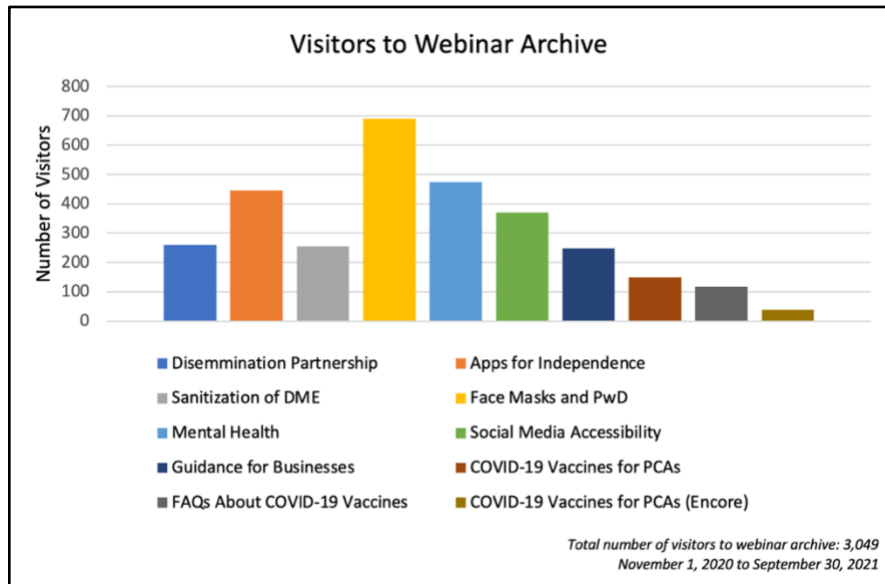
Other Product Forms

Other products were developed for the target audiences, some in online webinar, podcast, or video formats, some grounded in CDC guidance, and others that addressed related concerns. Those products not translated from CDC guidance were developed by CIDI and underwent review and approval by a CDC communications team. The products were developed and presented live during the project, then archived for on-demand access. The webinar series addressed topics related to COVID-19 and its impact on people with disabilities.

Webinars addressed a wide range of pandemic-related issues. After presentation through live registration, all were archived for on-demand use. Figure 2 reflects the greater interest in three topics: Face Masks, Mental Health and Resilience, and Apps for Independence.

Two additional webinars addressed the barriers to vaccination and vaccine reluctance. Brief guidance videos were created for people with intellectual or developmental disabilities.

Figure 2: Visitors to Webinar Archive



DISSEMINATION METHODOLOGY

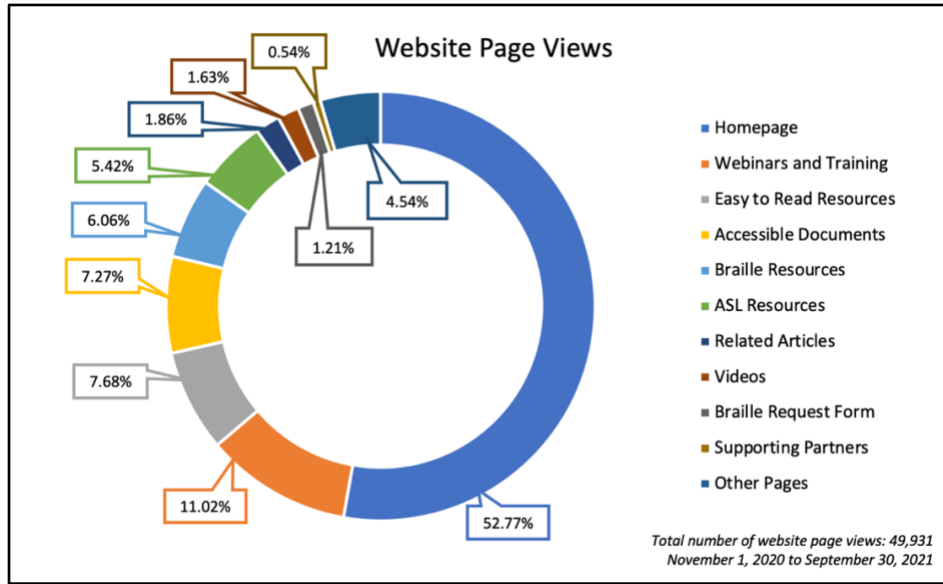
Dissemination of products and messages relies heavily on information and communications technologies (ICT) but encompasses other channels to reach some target audiences. The plan engages diverse partners in a multi-tiered network to optimize reach to as many people with disabilities as possible.

Network Hubs

The entire dissemination/distribution process is heavily dependent on the use of two primary network “hubs,” the CDC website and a microsite developed and hosted at Georgia Tech, for distribution of most of the alternative format content described above. The CDC website hosts its usual offerings of COVID-19 guidance, and was enhanced with improved accessibility of web pages, links to new videos produced during the project, new COVID-19 guidance using simplified text (under the general “easy-to-read” label), and links to the new microsite for additional content in braille and simplified text. The microsite provides access to braille resources, Word documents, PDF files, ASL videos, simplified text documents, archived webinars, training, and other resources.

The chart on the next page illustrates the usage of the entire range of products developed to make COVID-19 guidance accessible.

Figure 3: Website Page Views



Building a Network of Partners

Key partners (mostly national organizations) were identified for each of the four target disability audiences. The goal was not solely to identify channels with greater reach, but a combination of channels to reach directly as many members of each audience segment as possible through a combination of national advocacy organizations for people with disabilities, advocacy organizations for specific disabilities, organizations and agencies that provide services for people with disabilities, affiliate groups, healthcare providers, schools, and independent living organizations. The larger organizations served as nodes for secondary dissemination to service providers, families, and individuals with disabilities.

A key strategy to achieve mass dissemination used existing CDC and CIDI networks. CIDI has a wide network of relationships with disability-related organizations at both state and national levels. Tools for Life (TFL), Georgia’s Assistive Technology Act Program (based at CIDI) serves all ages and all disabilities in the state, directly or through partners. TFL is one of 56 state and territorial AT Act Programs, and it plays a national role in providing technical assistance to the other programs. Like TFL, all programs have statewide affiliates, thereby creating a national network of disability-related services providers. Tools for Life and the Pass It On Center have extensive experience partnering with other AT Act Programs to respond to emergencies.

CIDI provides services to 70% of the degree-granting postsecondary institutions in the U.S. through its management of the Access Text Network, direct services to students (e-text, captioning, described media, and braille), and relationships with the Disability Services Officers that use the services or CIDI’s Student Accommodations Manager software.

CDC relationships and distribution networks encompass state public health networks and health promotion campaigns with a broad focus on disabilities and several CDC-funded disability organizations.

Members of the project team and CDC Foundation partners identified additional channels for dissemination.

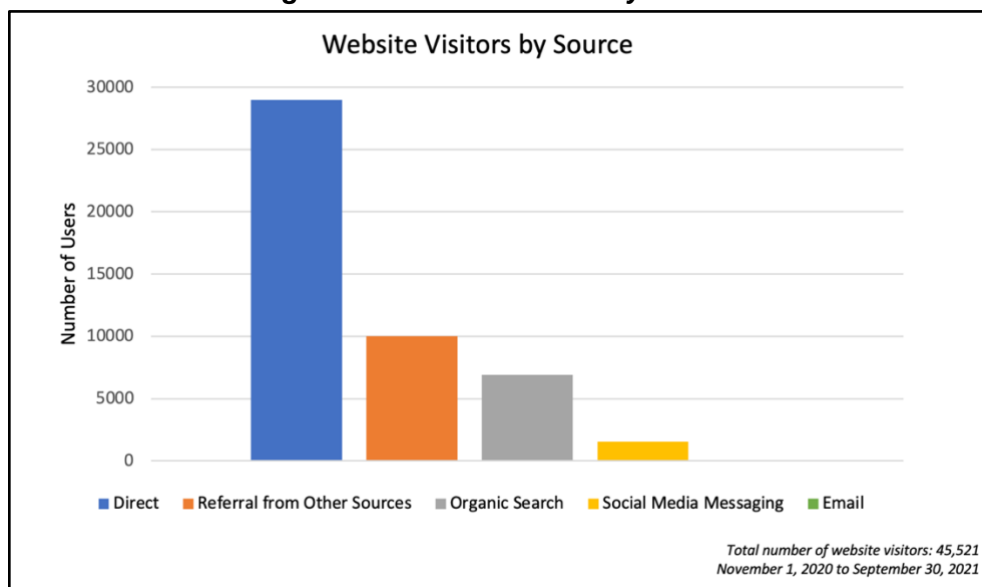
Three coalitions that focus on disability were recommended by the American Association on Health and Disability (AAHD), another project partner. The Friends of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) is a coalition of organizations that support the work of NCBDDD. Liz Persaud, project Co-Principal Investigator, presented an overview of the project to the Executive Committee of the Friends of NCBDDD on Oct. 27.

The Consortium of Citizens with Disabilities (CCD) is a coalition of national disability organizations. AAHD is an active member of the CCD Health Task Force, CCD LTTS Task Force, and CCD Emergency Management Task Force.

Members of the American Public Health Association (APHA), Disability Section, are disability researchers, disability advocates, and people with disabilities. Liz Persaud presented at the APHA Annual Meeting Disability Chairs Forum in October.

The project used the compilation of these contact lists and growing partnership channels in massive direct dissemination of social media messages and invitations to webinars. The webinars shared critical guidance and offered continuing education credits at no cost to participants. All included invitations to partner in the dissemination effort. The massive messaging campaigns preceding each online seminar reached more than 6,000 people and resulted in more than 8,000 registrations for the series of 8 webinars developed to supplement CDC guidance.

Figure 4: Website Visitors by Source



The effectiveness of the massive messaging is reflected in the diversity of the sources of visitors. The majority (61%) came from direct search informed by messaging through the partner networks with an additional 21% connected directly by referral through a link from other sites.

DISTRIBUTION OF COVID-19 RELATED CONTENT

The primary products for dissemination were the most widely used CDC guidance documents (as determined by web metrics) and those identified as most needed by people with disabilities. The most needed documents were identified through feedback from people with disabilities, subject matter experts (SMEs), and professionals who serve people with disabilities. The compilation resulted in 34 titles with additional products and related resources.

The agreed-upon list of CDC products was converted into scripts for ASL videos using the process described earlier. CDC produced the videos in cooperation with the Federal Emergency Management Agency (FEMA). The resulting videos were posted to the CDC YouTube channel and made available through links on both the CDC site and the Georgia Tech microsite.

The sense of urgency dictated an effort to reach an information consumer, rather than waiting for the consumer to seek the information. The braille dissemination plan was to strategically assist individuals who are blind or have vision-related disabilities whether the persons need embossed braille delivered to their home, braille-ready files delivered to their refreshable braille display, or fully accessible documents available for their screen-reader so they can access needed COVID-19 information. Blind individuals who use embossed braille face a significant challenge in obtaining timely access to text-based content. Embossed braille is the only product that requires a unique physical distribution strategy.

CIDI's Braille Services Unit transcribed eight of the highest priority products into braille and combined them into a single package. The project provides the CDC guidance to braille users by partnering with their usual providers and by accepting direct requests through the GT microsite. Existing braille providers may be libraries or schools that became dissemination partners with the project. The project makes freely available for their customers the packets of embossed braille guidance. The alternative point of access is the microsite where an individual may place a direct request for braille products. Embossed (hard copy) braille is produced and disseminated to key network partners for delivery to existing customers for braille.

A large portion of the braille produced at CIDI is science, technology, engineering, and math (STEM) content provided to K–12 and college students. CIDI contacted organizations that had requested braille in the past 3 years to seek dissemination assistance for embossed braille and promotion messaging to students being served.

CIDI used its long-standing collaboration with the Georgia Libraries for Accessible Statewide-Services (GLASS) to assist in promoting messaging and distribution of embossed braille through the National Library Service for Blind and Print Disabled (NLS).

CIDI also used its role as a member organization of the Braille Authority of North America (BANA) to request dissemination assistance for embossed braille and promotion messaging. CIDI provided packets of embossed braille to each organization. The Braille team ships the packets of CDC guidance in embossed braille to the partner organizations. Each packet is placed in a padded envelope with a Free Matter for the Blind mailing address label. The padded envelopes are boxed and shipped via UPS to the partner organizations. Partners add the mailing labels of their customers and mail the envelopes at no cost. As partners, representatives of each organization promote the availability of the COVID-19 braille packets and the request feature on the microsite to their fellow librarians, patrons, or partners through their existing channels.

Key COVID-19 guidance documents were prepared for those reading below 3rd grade level by using the Guidelines for Minimizing the Complexity of Text. The products were posted to the CDC website and the Georgia Tech microsite. The Guidelines were posted on the microsite and made freely available to potential users of the new format.

Channels for Disseminating Information about Alternate Formats

Trusted partners are important, and that often requires more local connections. The support of trusted organizations increases the effectiveness of the message and the likelihood that the CDC will be considered in the future for needed health guidance. The overall dissemination model relies on repeated messages through social media channels and the informal amplification of those messages to pull users to the network hubs or to webinars.

In choosing partners for dissemination, emphasis was placed on identifying some that are involved directly with each of the major disability audiences in addition to the larger encompassing community of individuals with disability. This focused identification targeted smaller audiences within large disability segments.

The Dissemination Team explored options for establishing dissemination partnerships. On Nov. 10, 2020, CIDI launched its partner recruitment campaign with a webinar. The team sent information about the online webinar and the project to approximately 5,000 identified contacts through CIDI's existing networks of disability contacts. Participants were invited to explore partnerships through a follow-up survey. In the two weeks following the launch, 18 organizations became dissemination partners, including significant distributors of embossed braille.

Social Media Messaging

Messages (communication about the products) contain key points that are appropriate to the audience and provide components to foster interaction.

To minimize the level of effort required by the partners, CIDI used internal marketing and social media specialists to devise messages in different sizes. These consist of "small" messages through Twitter and Facebook that add information to accompany the link, and "large" messages through blogs, posts, guest

articles, newsletters, and Mailchimp. The messages were delivered to partners to support dissemination of specific products as new products were added to the websites.

Team members developed larger, longer messages to promote new webinars, new batches of products, or significant new activities. For example, messages promoting each of the 8 webinars were disseminated to more than 5,000 contacts using the combined networks of CIDI and selected disability organizations within CDC. Given that most were organizational contacts, it is not possible to calculate a precise reach. A report of partner estimates of email, direct mail, Facebook, Twitter, Instagram, websites, newsletters, and listserv contacts results in an approximated total reach of 2.4 million.

Tracking Dissemination

Content dissemination is measured quantitatively through product distribution tracking and web metrics. A monthly report tracks current month and cumulative dissemination using:

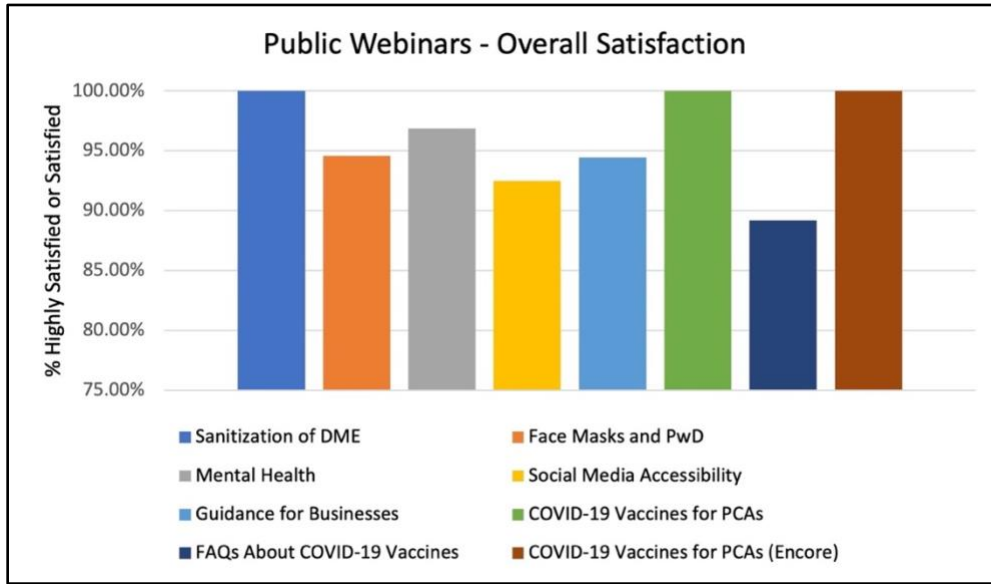
1. Website analytics
 - Number of unique visitors (by gender, age, location)
 - Total number of visits
 - Referrals from partner sites (and others)
 - Conversion rate (completed a transaction: viewed a product, downloaded a file, etc.)
 - Top 10 pages viewed
 - Video views
 - Demographics of visitors (age and location)
2. Social media analytics
 - Views
 - Link clicks via bit.ly
 - Shares/Re-tweets
 - Replies/Comments
3. Individual product metrics
 - Braille: embossed, delivered
 - Braille: requests for embossed products
 - Braille: PDF file downloads
 - Registrations and attendance for webinars

The utility of and satisfaction with guidance is measured qualitatively through user satisfaction surveys, open-ended comments (satisfaction, knowledge gained, value), and voluntary contacts to sites (new needs, comments on performance, value, etc.).

Only the webinar that addressed business and workplace issues fell short of the 90% satisfaction mark.

Open-ended comments were dominated by expressions of thanks and commendations on the content.

Figure 5: Public Webinars – Overall Satisfaction



“Great information. Thank you.”

“I loved the variety of information and ideas given throughout the webinar.”

“The information presented was timely and relevant. I appreciate that it covered a wide range of scenarios to include sensory disorders and PTSD.”

“I plan to share this information with the facilities and schools in which I provide services. Very helpful and comprehensive.”

Some feedback offered suggestions that helped us to improve presentation or delivery of content in subsequent presentations.

“I would suggest also posting the links of the references (that were on the slides) also in the chat.”

“I wish the program had been 1.5 hours to share more lived experiences.”

“There were lots of good questions asked at the end of the webinar. Will you be able to format a Q&A document that includes those questions and answers from this session and submit it to all attendees?”

Others suggested a longer program to permit time for questions or sharing. While we were not able to extend programs, all webinars were archived for on-demand use, and some comments made note of how helpful this was. For example:

“I enjoyed the ability to have access to the resources online, at my leisure due to COVID-19 and my schedule. I can take my time and really study the material. Thank you.”

OUTCOMES OF THE DISSEMINATION MODEL

In its first six months of operation, the Georgia Tech microsite hosting the growing body of accessible guidance and project resources had 29,804 visitors and more than 70,000 page views. The portal was used to accept requests for embossed braille and to make available accessible Word and PDF files, ASL videos, and simplified text products. It is not possible to calculate the multiplier effect of product availability and pass-it-on benefit of actual product (reported high in the community of braille users) or verbal guidance.

The development of the Guidelines for Minimizing the Complexity of Text (which are also freely available on the microsite) is a major milestone in reaching an unserved audience (those with cognitive disabilities) with critical health guidance in a new format. Amassing contacts for project activities resulted in new outreach initiatives with AAHD, a vaccine collaboration with 15–20 national organizations, additional outreach in partnership (with joint webinars) with the Pacific ADA and the Southeast ADA Centers, and guest speaking engagements by the Principal Investigator and Co-Principal Investigator.

BENEFITS OF THE DISSEMINATION MODEL

The building of the dissemination network reinforces existing emergency response activities at CIDI and affords a model for more nimble response to future and different emergencies. The responses suggest that additional capacity for response may have greater impact.

News of project activities focused on the improvement of accessible communications is gaining interest and commitment. The Georgia Council on Developmental Disabilities initiated a contract with CIDI to provide organization-wide training and guidance for Universal Design and accessibility.

Key new partnerships were forged with and among several organizations partnering in the dissemination. These promise to result in future research and services related to enhanced accessibility in communications.

DISCUSSION AND CONCLUSION

The development of a new alternate format is a major achievement. Unfortunately, this project and the building of the dissemination network also highlighted the need for more extensive commitment to Universal Design, inclusion, and best accessibility practices. Accessible communication with people with

disabilities is hindered by the failure to use technologies at the fingertips of most computer users. More pervasive education about accessible communications is needed.

While devising the dissemination network, it became obvious that most organizations could benefit from learning how to leverage the multitudes of contacts into actionable forms of communication to support emergency response. Shared experiences highlighted opportunities to capitalize on the strengths in other organizations to support future research, education, and service.

The COVID-19 pandemic highlighted the absence of and the need for a sustainable framework for emergency communication with people with disabilities. Persistent confusion, misunderstanding, and distrust about critical health care guidance is hampering the achievement of critical goals and endangering the well-being of millions. The pandemic highlighted the impact of emergencies on marginalized populations.

This project, like most projects, faces the conundrum of how to sustain the important gains and how to use the resources developed. CIDI will attempt to collaborate with existing and new partners to identify the opportunities.

DECLARATIONS

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