Assistive Technology

Outcomes and Benefits

Published by the Assistive Technology Industry Association (ATIA)

Volume 16 Issue 2

Summer 2022

Providing Accessible Public Health Materials for Individuals with Disabilities During a Pandemic: Lessons Learned from COVID-19

Mark Harniss
Guest Editor

Anya S. Evmenova
Editor-in-Chief

Carolyn P. Phillips
Associate Editor

ATiA Assistive Technology Industry Association

ISSN 1938-7261

Assistive Technology Outcomes and Benefits Accessible Public Health Materials During a Pandemic: Lessons Learned from COVID-19

Volume 16 Issue 2, Summer 2022

Assistive Technology Outcomes and Benefits (ATOB) is a collaborative peer-reviewed publication of the Assistive Technology Industry Association (ATIA). Editing policies of this issue are based on the Publication Manual of the American Psychological Association (7th edition) and may be found online at www.atia.org/atob/editorialpolicy. The content does not reflect the position or policy of ATIA and no official endorsement should be inferred.

Peer Reviewers for ATOB Volume 16 Issue 2 Accessible Public Health Materials During a Pandemic: Lessons Learned from COVID-19

The Editorial Board would like to thank the peer reviewers who generously donated their time and talent to reviewing manuscripts for this Volume 16 Issue 2 of ATOB.

Melissa Ainsworth
Meenakshi Das
Alissia Garabrant
Hillary Goldthwait-Fowles
Carmelina Hollingsworth
Roba Hrisseh
Jennifer Monahan
Laura Nichols
Nancy Quick
Sarah Parker Harris
Kial-Ann Rasmussen
Belinda Rudinger
Meg Ann Traci
Tammy Thompson-Cooke
Patricia Wright

Assistive Technology Outcomes and Benefits Editorial Policy

Aim and Scope

Assistive Technology Outcomes and Benefits, published by the Assistive Technology Industry Association, is an open access, peer-reviewed journal that publishes articles specifically addressing the benefits and outcomes of assistive technology (AT) for Persons with Disabilities across the lifespan. The journal's purpose is to advance the AT industry by (a) fostering communication among stakeholders interested in the field of AT, including manufacturers, vendors, practitioners, policy makers, researchers, consumers with disabilities, and family members; (b) facilitating evidence-based demonstrations and case-based dialogue regarding effective AT devices and services; and (c) helping stakeholders advocate for effective AT devices and services.

Assistive Technology Outcomes and Benefits invites for consideration submissions of original papers, reports and manuscripts that address outcomes and benefits related to AT devices and services. These may include (a) findings of original scientific research, including group studies and single subject designs; (b) qualitative and mixed methods studies, such as focus group and structured interview findings with consumers and their families regarding AT service delivery and associated outcomes and benefits; (c) marketing research related to AT demographics or devices and services; (d) technical notes and usability studies regarding AT product development findings; (e) project/program descriptions in which AT outcomes and benefits have been documented; (f) case-based reports on successful approaches to service delivery; and (g) consumer perspectives on AT devices and services.

Submission Categories

ATOB welcomes scholarly contributions. However, many stakeholders engaged in the field of AT do not have an academic background. ATOB offers a unique opportunity for these stakeholders to contribute their expertise and experience in the context of achieving successful outcomes and beneficial impacts. ATOB understands that many potential authors may lack experience in authoring papers for peer-reviewed journal publication. Therefore, the ATOB Editorial Board is pleased to offer assistance in preparing and refining relevant submissions. Articles may be submitted under three categories:

Voices from the Field

Articles submitted under this category should come from professionals who are involved in some aspect of AT service delivery with persons having disabilities, or from family members and/or consumers with disabilities. Submissions may include case studies, project or program descriptions, approaches to service delivery, or consumer perspective pieces. All submissions should have a clear message and be written with enough detail to allow replication of results. See ATOB Editorial Policy for more details.

Voices from Industry

Articles submitted under this category should come from professionals involved in developing and

marketing specific AT devices and services. Case studies, design, marketing research, or project/program descriptions are appropriate for this category. See ATOB Editorial Policy for more details.

Voices from Academia
Articles submitted under this category should come from professionals conducting research or development in an academic setting. Submissions are likely to include applied/clinical research, case studies, and project/program descriptions. See ATOB Editorial Policy for more details.

Types of Articles

Within each of the voices categories, authors have some latitude regarding the type of manuscript submitted and content to be included. However, ATOB will only accept original material that has not been published elsewhere, and is not currently under review by other publishers. Additionally, all manuscripts should offer sufficient detail to allow for replication of the described work.

Applied/Clinical Research
This category includes original work presented with careful attention to experimental design, objective data analysis, and reference to the literature.

Case Studies
This category includes studies that involve only one or a few subjects or an informal protocol.

Design
This category includes descriptions of conceptual or physical design of new AT models, techniques, or devices.

Marketing Research
This category includes industry-based research related to specific AT devices and/or services, demographic reports, and identification of AT trends and future projections.

Project/Program Description
This category includes descriptions of grant projects, private foundation activities, institutes, and centers having specific goals and objectives related to AT outcomes and benefits.

Approaches to Service Delivery
This category includes descriptions of the application of assistive technology in any setting (educational, vocational, institutional, home-life) to improve quality of life for people with disabilities.

Consumer and Caregiver Perspectives
This category offers an opportunity for product end users, family members, and caregivers to share their experiences in achieving successful outcomes and benefits through the application or use of AT devices and services.

Mandatory Components of All Articles

Authors must include a section titled Outcomes and Benefits containing a discussion related to outcomes and benefits of the AT devices/services addressed in the article.

Authors must include a short description of the article's target audience and indicate the article's relevance to that target audience. Authors may describe their work as it relates to more than one audience and should specify the value that each group may derive from the work.

Publishing Guidelines

Review detailed Manuscript Preparation for Authors for information on formatting requirements and submission guidelines.

For More Information

Please see ATOB's Editorial Policy at http://www.atia.org/at-resources/atob for more details regarding the submission and review process, ATOB's Copyright Policy, and ATOB's Publication Ethics and Malpractice Statement.

Assistive Technology Outcomes and Benefits Accessible Public Health Materials During a Pandemic: Lessons Learned from COVID-19

Volume 16 Issue 2, Summer 2022

Table of Contents

Assistive Technology Outcomes and Benefits
Volume 16 Issue 2, Summer 2022, pp. ix-xii
 ISSN 1938-7261
Available online: www.atia.org/atob

Introduction to Volume 16 Issue 2

Mark Harniss, Ph.D.

University of Washington

Corresponding Author
Mark Harniss
Department of Rehabilitation Medicine
University of Washington
Box 357920
Seattle, WA 98195-7920
Phone: (206) 685-0289
Email: mharniss@uw.edu

The COVID-19 pandemic highlighted how important it is to have access to understandable public health information. In a media climate with lots of mixed messages, people needed information from reputable sources, in formats that were accessible, and in language that was understandable. The pandemic highlighted ongoing inequities in access to information for people with disabilities. As businesses and schools went online, some services and supports became harder to access, and the inaccessibility of websites and electronic documents became more problematic. People with disabilities have the right to effective communication that is at least as effective as that offered to people without disabilities, but the implementation of that right has often been inconsistent.

The goal of this special issue was to define public health information access issues and to share best practices, lessons learned, and successes in the development and dissemination of public health information in general, and specifically as it relates to ensuring that individuals with disabilities receive accurate and actionable information during pandemics. Much of the work reported here focuses on a communications initiative funded by the National Foundation for the Centers for Disease Control and Prevention (CDC Foundation). The project focused on four groups: individuals who are blind and use braille, individuals who are deaf or hard of hearing and use ASL, people with limited literacy skills who benefit from simplified text, and those with mobility limitations. Led by a team at Georgia Tech's Center for Inclusive Design and Innovation (CIDI), with partners from the Center for Literacy and Disability Studies at UNC-Chapel Hill, DeafLink, and the American Association on Health and Disability (AAHD),

the project aimed to improve COVID-19 communications and disseminate best practices to ensure that communications are accessible for people with disabilities in future emergency or disaster situations.

This volume includes two articles in **Voices from Academia**. First, in their article *Minimizing the Complexity of Public Health Documents: Making COVID-19 Documents Accessible to Individuals who Read Below the Third-Grade Level*, Sofia Benson-Goldberg, Lori Geist, Ben Satterfield, and Karen Erickson describe the conduct of a rapid review of the research literature on text complexity and plain language. Findings from the rapid review guided the development of a set of Minimal Text Complexity (MTC) Guidelines. These guidelines address whole text issues (e.g., format, semantics) as well as sentence and word-level issues. The MTC Guidelines differ quite a bit from traditional plain language recommendations. The authors then applied the guidelines to 27 CDC documents about COVID-19 to develop simple, easy-to-read documents addressing a range of important topics like wearing a mask, cleaning and disinfecting, and testing. The resulting simplified documents had fewer words, shorter sentences, and were easier to read based on readability metrics. This important work addresses an often-ignored access issue related to reading literacy.

In a second article, Ben Satterfield and Zerrin Ondin describe *A Needs Assessment of COVID-19 Guidance for Adults with Developmental Disabilities*. The authors conducted a rapid assessment to determine whether current CDC guidance materials were readable and understandable by adults with intellectual and developmental disabilities (I/DD). Specifically, the authors interviewed adults with I/DD about their experience with CDC COVID-19 materials as well as their general experiences and information needs related to COVID-19. In addition, adults with I/DD were asked to visit a CDC webpage on face masks and provide their impressions. Finally, the authors conducted group interviews with caregivers of the adults with I/DD. Findings from the rapid assessment indicate that CDC materials were used rarely and were not easily understandable by the adults with I/DD. Adults with I/DD relied more on family and care providers for information, even though most of them had access to devices and internet connections. Findings from this rapid assessment highlight the need for accessible and understandable health information for this audience.

Three articles in this volume are **Voices from Industry**. Sheryl Ballenger's article addresses *Access for Deaf and Hard of Hearing Individuals in Informational and Educational Remote Sessions*. Specifically, she discusses how the pandemic disrupted information access for people who are Deaf or hard of hearing. The rapid move to online, virtual interactions made it difficult for organizations and individuals to access ASL interpretation and captioning services (i.e., Speech-to-Text-Services—STTS). Many platforms added Automatic Speech Recognition (ASR) as an option. Ballenger explores the extent to which ASR provides adequate access to spoken speech by conducting a comparative analysis of the accuracy of ASR produced transcripts to STTS. She found that ASR transcripts are not fully accurate and that, more importantly, they may make errors in ways that reduce meaning, while human STTS may be able to address the intended meaning in a conversation more fully. She concludes that ASR may be appropriate in low stakes, but not high stakes interactions.

K. James Monroe and Valerie Morrison's article, *Creating Accessible Infographics: Describing Scientific Data in Ways Everyone Can Understand*, describes the challenges in textually describing complex images. They review the literature on how people learn from images and the cognitive load associated with image processing and they discuss how text descriptions of images can help not only people who are blind, but others who may have difficulty interpreting complex images. They share their extensive professional experience writing alternative text and demonstrate how their recommendations can be implemented using several example CDC infographics. Their pragmatic, detailed recommendations provide a solid foundation for anyone wishing to improve descriptions of images.

Finally in this section, Norah Sinclair, Sheryl Ballenger, and Maureen Linden's article, *Inclusive Design Thinking for Health Messaging in American Sign Language during the COVID-19 Pandemic: A Case Study Brief*, provides a case study highlighting an inclusive design thinking framework that supported the development of accessible, culturally relevant COVID-19 materials for ASL speakers. Their case study demonstrates how they worked with content experts and ASL interpreters to craft public health guidance that was accurate, easy to understand and appropriately translated to ASL. The authors also conducted a needs assessment to understand challenges related to finding ASL content online. They report several practical suggestions for increasing the visibility of ASL content.

Four articles in this volume are **Voices from the Field**. In their article, *Closing the Information Gap: Making COVID-19 Information Accessible for People with Disabilities*, Sarah Anderson, Alina Flores, Laura Baldwin, Carolyn Phillips, and Jennifer Meunier provide an overview of the CDC Foundation-funded communications initiative that supported the work detailed in many of the articles in this volume. The project began with needs assessment and evaluation of the CDC website for accessibility. It then supported development of essential COVID-19 materials in multiple accessible formats, including braille, American Sign Language (ASL), simplified text, and other alternative formats. Finally, it identified additional gaps in COVID-19 information (e.g., adaptations to face masks for people with various disabilities), conducted a webinar series on these topics, and engaged in extensive dissemination of the products produced. The authors discuss the challenges they experienced in conducting this work within the context of a rapidly changing public health crisis.

In their article *"Include Me": Implementing Inclusive and Accessible Communications in Public Health*, Alina Flores, Jennifer Meunier, and Georgina Peacock report on their experience planning and executing a Public Health Grand Rounds that maximized accessibility and understandability for participants with disabilities, including people with I/DD. Their work highlights the importance of proactively planning for broad access as a part of organizational culture, rather than as a response to a request for accommodation. In addition, they underscore the importance of including people with disabilities in the planning and implementation of educational programs.

Liz Persaud reports on *Building an Effective Model to Disseminate Accessible COVID-19 Guidance*. She describes efforts to ensure that COVID-19 public health materials developed in alternative formats reach the people who need it. This work involved understanding the discrete audiences for the materials and the appropriate methods and channels of dissemination. Persaud details the dissemination methodology

for all audiences and alternative formats developed in the CDC communications initiative. Her work highlights the effort, resources, and planning necessary to ensure that important public health information reaches audiences who need it during a public health crisis.

Finally, Johan Rempel discusses *The Importance of Braille During a Pandemic and Beyond*. Rempel begins with a discussion of the continuing relevance of braille within the context of other technologies (e.g., text-to-speech technologies). He then describes a qualitative study in which individuals who are blind were interviewed about their format preferences for receiving COVID-19 information (i.e., embossed braille, refreshable braille display, text-to-speech). In this small study, all participants wanted the option to have embossed braille, despite having refreshable braille displays. Reasons include increased understanding and retention, reading speed, and ease of use. Rempel's work highlights the need to consider user format preferences when considering the development of alternative formats.

CONCLUSION

The articles in this volume provide a road map for federal and state agencies, nonprofits and educational organizations, and businesses who want to ensure that health information developed and disseminated during a public health crisis is understandable, accessible, and usable by most people, especially those with disabilities. Public health crises, like the COVID-19 pandemic, can stress systems and highlight gaps in information access. Organizations should build accessibility into their organizational culture, so they have developed the skills and mindset to ensure access even when systems are stressed.

DECLARATIONS

This content is solely the responsibility of the authors and does not necessarily represent the official views of ATIA. No financial disclosures and no non-financial disclosures were reported by the author of this paper.

Assistive Technology Outcomes and Benefits
Volume 16 Issue 2, Summer 2022, pp. 1-15
 ISSN 1938-7261
Available online: www.atia.org/atob

Voices from Academia

Minimizing the Complexity of Public Health Documents: Making COVID-19 Documents Accessible to Individuals Who Read Below the Third-Grade Level

Sofia Benson-Goldberg, Ph.D.[1], Lori Geist, Ph.D.[1], Ben Satterfield, Ed.D.[2], Deidra Bunn, SLP[2], and Karen Erickson, Ph.D.[1]

[1]Center for Literacy and Disability Studies, Department of Allied Health Sciences
University of North Carolina at Chapel Hill
[2]Center for Inclusive Design and Innovation
Georgia Institute of Technology

Corresponding Author
Sofia Benson-Goldberg
University of North Carolina-CH
CB #7335 UNCH-CH
Chapel Hill, NC 27599-7335
Email: sofia_bensongoldberg@med.unc.edu

ABSTRACT

The Centers for Disease Control and Prevention (CDC) is a trusted source for public health information, but people must be able to access and understand that information for it to be used. The CDC and the CDC Foundation recognized the need to ensure that its guidance documents related to COVID-19 were accessible to the full range of individuals with disabilities, including those with intellectual and developmental disabilities who read or listen with comprehension at or below the third-grade level. In response to this need, they contracted with the Center for Literacy and Disability Studies (CLDS), Department of Allied Health Sciences, University of North Carolina at Chapel Hill, and the Center for Inclusive Design and Innovation, Georgia Institute of Technology, to create easy to read versions of a collection of guidance documents related to COVID-19. The CLDS began the process by seeking existing guidelines or research to support the creation of these documents. When no such information was

located, the CLDS conducted a systematic review of the literature and developed the *Minimized Text Complexity Guidelines*. The outcomes and benefit of this work include improved access to critical information regarding COVID-19 for individuals with intellectual and developmental disabilities, as well as other adults who read and listen with comprehension below a third-grade level.

Keywords: accessible text, health literacy, low-literacy resources

MINIMIZING THE COMPLEXITY OF PUBLIC HEALTH DOCUMENTS: MAKING COVID-19 DOCUMENTS ACCESSIBLE TO INDIVIDUALS WHO READ BELOW THE THIRD-GRADE LEVEL

An estimated 56 million adults in the United States have basic or below-basic reading skills (Lesgold & Welch-Ross, 2012). While these adults are able to read simple words and phrases in familiar contexts, they are largely unable to do so with comprehension. Simultaneously, more than 61 million people in the United States live with a disability. Reading comprehension is consistently the academic area with the lowest outcome for all adults with disabilities (Wagner et al., 2006). Within this group, adults with intellectual disabilities are known to struggle with reading in general and reading comprehension in particular, with the population consistently scoring nearly three standard deviations below the mean on reading comprehension measures (Wagner et al., 2006).

Though poor reading comprehension has long been associated with negative outcomes for adults with and without disabilities (Johnson, 1985; UNESCO, 2005), it posed a significant threat during the COVID-19 pandemic. Most information regarding COVID-19 safety precautions was produced and disseminated in print formats. Unfortunately, the complexity of many of these materials was beyond the reading comprehension level of many people with intellectual and developmental disabilities. This presented a significant problem during the COVID-19 pandemic, as people with intellectual disabilities who contracted the virus were three (Rabin, 2020) to eight (Gleason et al., 2021) times more likely to die than those without intellectual disabilities. The risks of getting sick and dying from COVID-19 are compounded for people with intellectual disabilities from racial and ethnic minority groups who face additional inequities in social determinants of health (CDC, 2020). Lack of access to COVID-19 information due to difficulty comprehending text likely contributed to this. In general, limited access to health information has negative health implications and shines a light on the underlying factors contributing to the increased risks faced by people with intellectual disabilities in the current pandemic.

Section 508 of the Rehabilitation Act mandates that public-facing electronic communication content created by any Federal agency must be accessible for individuals with some disabilities (e.g., assistive technology devices can access information, closed captions are available on videos, etc.). However, the requirements fall short of ensuring that such communication content is accessible to all individuals with disabilities. One specific group that has been overlooked is people with and without intellectual and developmental disabilities who have extremely low literacy (i.e., reading and listening comprehension at the third-grade grade level or lower). Though plain language standards do exist (see

https://www.plainlanguage.gov/guidelines), there are currently no concise guides for instructing federal agencies on how to expand communication reach and accessibility to include those people who read with comprehension below a third-grade level.

In response to this problem, and in order to create a set of easy to read documents based on the COVID-19 guidance documents produced and disseminated by the Centers for Disease Control and Prevention (CDC), a team from the Center for Literacy and Disability Studies (CLDS) Department of Allied Health Sciences at the University of North Carolina at Chapel Hill created the Minimized Text Complexity (MTC) Guidelines (Erickson et al., 2020) to inform writing text that is understandable to people with disabilities who read at or below a third-grade level. After developing the guidelines, the team at the CLDS worked in collaboration with a team from the Center for Inclusive Design and Innovation, Georgia Institute of Technology, to apply them to author a set of simplified, easy to read documents related to COVID-19.

TARGET AUDIENCE

There are two primary audiences for the work described here. The first audience includes the 56 million adults in the United States who have below-basic reading levels (Lesgold & Welch-Ross, 2012), including the majority of adults with moderate to severe intellectual and developmental disabilities. Our goal in creating the MTC Guidelines and applying them to the CDC's guidance regarding COVID-19 was to make the documents accessible to this entire group of individuals. Our secondary audience includes everyone who has a role in creating health and other documents for people in our primary audience. This secondary audience includes a broad coalition of people including: (a) people who devote their lives to communicating critical health information to the public; (b) administrators and other personnel in healthcare and education settings who occasionally prepare documents to communicate critical information; (c) researchers who are required to make their consent documents and other materials accessible to the people who participate in their research; and (d) anyone who wants to create cohesive and easy to read information for adults who read or listen with comprehension at a third-grade level or lower.

LITERATURE REVIEW

Plain Language Due

Since the passing of the Plain Writing Act of 2010, the law now requires that all federal agencies use "clear Government communication that the public can understand and use" (p. 1). There are official plain writing guidelines that accompany the Plain Writing Act (https://www.plainlanguage.gov/guidelines). The guidelines are broadly organized around audience considerations, organizational practices, and writing principles; with writing principles further broken down to word, sentence, paragraph, and section-level guidelines. Writers are encouraged to use lists, tables, bullets, illustrations, and headings to make complex materials easier to understand. Word-level guidelines include using (a) active voice (b) contractions, (c) pronouns, and (d) short, simple words.

Explicit training is necessary to support experts in using plain language in their written and oral communications; furthermore, even with training, experts require multiple passes back and forth with another expert in order to achieve sufficiently easy texts (Hadden, 2015). This suggests that much time and attention is required in order to achieve texts that are compliant and consistent with plain language guidelines. Widespread adoption has been found when easily accessible templates and procedures are provided for writers unfamiliar with how to implement plain language guidelines (Hadden et al., 2017). While plain language guidelines generally result in texts that have readability scores between sixth and the eighth-grade levels, in certain contexts, plain language may be insufficient to lead to comprehension (Miles & Cottle, 2011).

Text Complexity

Text complexity refers to distinct properties of a text that exist regardless of reader or task (Mesmer et al., 2012). Properties that impact complexity include vocabulary, word density, sentence length, and text length (Hiebert, 2014). Importantly, this is different from text difficulty, which refers to how easy or difficult a text is for a given reader. Text difficulty differs from person to person, and task to task. In fact, difficulty might be viewed as a result of the relationship between the person, the task, and the text (McNamara et al., 1996).

Text complexity impacts learning from text in a number of ways. When text complexity is lower, people demonstrate greater comprehension of material (Treptow et al., 2007). For example, children have been shown to learn more new vocabulary words when reading texts that are less complex (Anderson, 1996). Furthermore, regardless of ability, people learn and retain more new information from expository texts when the text complexity level is lower than the level of text they typically read with comprehension (Allington et al., 2015). Given the demands to learn novel words and to retain new information to navigate COVID-19 guidance, minimizing text complexity was of the utmost importance.

Readability formulas such as Flesch-Kincaid and Lexile scores are often used to identify texts that might be easier to read. While these systems are helpful for sorting large groups of text, they provide little information about what specifically is impacting complexity in any given text (Hiebert, 2011; Hiebert, 2014). Furthermore, these formulas privilege text features that often fail to reduce complexity. For example, sentence length weighs heavily in these formulas, with texts with shorter sentences receiving lower readability scores than texts with longer sentences. This is problematic because shortening sentences does not necessarily improve comprehension (Arya et al., 2011), and in fact can impair comprehension (Beck et al.,1982), presumably because it interferes with cohesion (Graesser et al., 2004). In order to establish guidelines for producing texts that can consistently be read with comprehension by the target population, it was important to go beyond readability formulas, and identify specific text features that impact complexity.

Graphics, Icons, and Images

Pairing graphics with text is often assumed to be a way of creating resources that demand fewer cognitive skills and thereby help readers extract meaning from text, presumably by eliminating the need to decode words. As such, the recommendation is often made to add pictures, pictograms, or graphic symbols to

text in order to make it easier to read (e.g., Nomura et al., 2010; Office for Disability Issues, 2018). Adding pictures, pictograms, or graphic symbols might involve representing the meaning of an entire sentence, key ideas in a sentence, or all of the meaning and grammatical information in a sentence (Poncelas & Murphy, 2007). Unfortunately, there is little empirical support for any of these uses of pictures, pictograms, or graphic symbols to support text comprehension (Benson-Goldberg & Erickson, 2020; Erickson et al., 2010; Hurtado et al., 2014).

Pairing graphic symbols with individual words has been used successfully in the context of expressive communication for many decades (e.g., Samuels, 1967); however, use in the context of learning to read (Erickson et al., 2010) and supporting comprehension (e.g., Hurtado et al., 2014; Poncelas & Murphy, 2007) is limited. Nonetheless, guidelines regarding text accessibility continue to include recommendations for the inclusion of graphic symbols (e.g., Department of Health, 2010; Office for Disability Issues, 2018), and various stakeholders respond positively and enthusiastically to texts that are supported word-by-word with graphic symbols (Parson & Sherwood, 2015).

Other visual supports, such as infographics, pictograms, and pictures, are often assumed to support reading comprehension. While it is true that readers rate infographics as more user-friendly, comprehension assessments do not demonstrate an advantage for infographics (Buljan et al., 2018). Furthermore, the research suggests that adding any visual support to text makes reading with comprehension more difficult, as it not only requires the reader to alternate their visual attention between the text and the other visual information, but it also requires different neural mechanisms to process and understand the information (Fisher & Frey, 2014; Hegerty et al., 1991). When pictures or illustrations have been used successfully, they have been closely matched to explanatory text that was clearly understood by the reader (Houts et al., 2006). Unfortunately, beginning and very low-level readers who do not easily understand the text pay attention to unrelated details in images or otherwise attend to the pictures in ways that do not support their comprehension (Filippatou & Pumfrey, 2006).

Given the need to concentrate on maximizing comprehension of the COVID-19 guidance documents, it was important to consider the ways in which adding pictures, graphic symbols, and infographics to text often increase rather than decrease the text complexity, and interfere with comprehension. Careful attention was paid to the literature regarding use and placement of pictures, graphic symbols, and infographics in order to determine how best to leverage these in order to support comprehension and minimize complexity.

METHODS

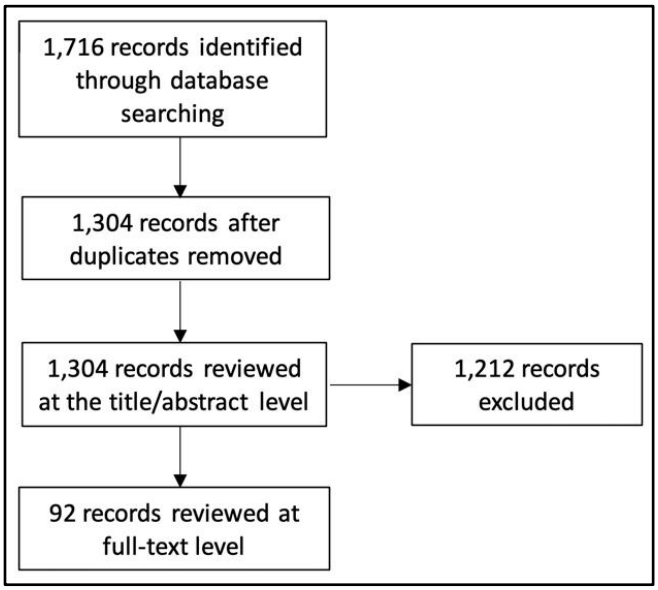
Rapid reviews are necessary to strengthen health policy and systems during time-sensitive events such as the COVID-19 global pandemic presents (Tricco et al., 2017). Similar to traditional systematic reviews, rapid reviews involve comprehensive reviews of the research literature with rigorous search and review strategies. Different from traditional systematic reviews, the goal is to progress rapidly to actionable understandings. The rapid review that informed the development of the MTC Guidelines involved a search of electronic databases including PsychInfo, MEDLINE, ERIC, CINAHL, Health Source:

Nursing/Academic Edition, and Education Full Text for records published within the last 10 years. These databases were chosen to get results from various subject areas. For studies to be included in the resulting guidance, they needed to address ways in which text could be written to support comprehension for any beginning or struggling readers, including those with developmental or intellectual disabilities.

Search Strategy

Initial searches were conducted in July 2020. Databases were searched using the keywords “plain language” or “simplified text” or “easy to read.” The term “text complexity” was then added because it is closely tied to research on reducing text difficulty at the lowest text levels. The use of these search terms resulted in 1,716 records that were uploaded to Covidence. After duplicates were removed, 1,304 records remained. Each was screened for relevance to the problem at the title and abstract level and 92 records were retained that related to increasing comprehension by using plain language or common, everyday words and excluded records on unrelated topics (*n* = 1,212). The 92 relevant records were then reviewed at the full-text level for appropriate recommendations. The search process is illustrated in Figure 1.

Figure 1: Summary of Review Results



RAPID REVIEW RESULTS: INITIAL GUIDELINES

The MTC Guidelines were written by examining the 92 retained records, as well as recent work completed regarding text complexity and beginning readers that was conducted by Cunningham et al. (2005) and Schuster and Erickson (2014). Records were read and examined to determine what text features are essential to supporting text comprehension for beginning and struggling readers.

The review of the resulting records indicated that plain language (https://plainlanguage.gov) was a necessary precondition of simplifying text, but insufficient to ensure comprehension for people with text comprehension skills below the sixth-grade level. Furthermore, it became clear that simply relying on

readability metrics would be insufficient to result in texts that would simultaneously support comprehension and retain the meaning that is critical to the COVID-19 guidance (Cunningham et al., 2018; Krieger et al., 2017; Leroy et al., 2013). While readability formulas are helpful for estimating the difficulty of texts relative to each other, they are insufficiently sensitive to syntactic and semantic features of text, as well as format features that have significant impacts on reading comprehension (DuBay, 2004; Krieger et al., 2017; Leroy et al., 2013).

As a result, it was important for the MTC Guidelines to focus on whole-text level guidelines, as well as specific sentence- and word-level guidelines that would support writers in producing texts that could be read easily, while still supporting comprehension of new information. The MTC Guidelines were organized into four sections: (a) whole-text-level guidelines; (b) sentence-level guidelines; (c) word-level guidelines; and (d) document-format guidelines. See https://www.med.unc.edu/ahs/clds/resources for full guidelines.

When compared to plain language guidelines, the MTC Guidelines differ in several important ways. First, the word-level guidelines are more specific and stringent. Where plain language suggests that authors should choose “short words,” the MTC Guidelines suggest that authors should ensure that at least 92% of words are amongst the most frequently occurring in written English. Furthermore, the MTC Guidelines require authors to reduce syllables per word, rather than word length in general. Similarly, content guidelines are more stringent in the MTC Guidelines. Where plain language guidelines begin by encouraging the writer to “think about the audience,” the MTC Guidelines go further by requiring that the document presents information that is directly relevant to the lives of the intended audience. If the content is not directly relevant, it should be excluded. Second, there are several plain language guidelines that were specifically contradicted in the MTC Guidelines. For example, plain language guidelines encourage using contractions, negation, and many useful headings, including questions, statements, and topics. None of these recommendations appear in the MTC Guidelines. In fact, contractions and negations are to be avoided entirely. Furthermore, headings are to be single informative statements of eight words or less. Third, where plain language guidelines make the general suggestion that authors design documents for easy reading, MTC Guidelines offer specific recommendations in regard to layout and organization for the target population.

APPLICATION OF GUIDELINES TO CDC COVID-19 EMERGENCY RESPONSE MATERIALS

The MTC Guidelines were applied to a total of 25 documents, prioritized by project staff from the CDC Foundation (CDC-F) and the CDC. The goal was to rapidly produce documents that conveyed the content deemed most critical within each document to help the target audience safely navigate the COVID-19 pandemic. Documents were extracted directly from html links provided by the CDC. The text was copied into worksheets, with text sectioned by content. This text was then annotated to indicate which MTC Guidelines needed to be applied to every section of text. At least two researchers trained in the application of MTC Guidelines then authored simplified versions of each section of text on the worksheet.

These solutions were compiled and compared by the first and last authors in order to arrive at documents that conveyed the most critical content, while adhering to the MTC Guidelines.

Results from First Ten Documents

The first ten documents simplified using the MTC Guidelines were reviewed for accuracy and relevance by project staff at the CDC-F and then cleared by appropriate offices at the CDC before they were posted on the CDC website. The ten documents can be accessed from the CDC website (https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/index.html) and a microsite created by the Center for Inclusive Design and Innovation at Georgia Tech (https://cidi.gatech.edu/covid/easytoread). The ten documents included in the analysis that follows are listed in Table 1.

Table 1: Simplified Document Titles and URLs

Document Title	URL
COVID-19 Can Make You Feel Sick	https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/symptoms-testing.html
Wearing a Mask	https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/diy-cloth-face-coverings.html
COVID-19 Safety	https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/prevent-getting-sick/prevention.html
The Spread of COVID-19	https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/prevent-getting-sick/how-covid-spreads.html
Clean and Disinfect at Home	https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/prevent-getting-sick/disinfecting-your-home.html
Caring for Someone with COVID-19	https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/if-you-are-sick/care-for-someone.html
Test for Current Infection	https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/testing/diagnostic-testing.html
Protect Animals from COVID-19	https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/service-therapy-animals.html
Decisions about School and Remote Learning	https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/schools-childcare/decision-tool.html
Protect Children at School	https://www.cdc.gov/coronavirus/2019-ncov/easy-to-read/parent-checklist.html

The following metrics were tabulated for both the original and the documents simplified using the MTC Guidelines: (a) total word count; (b) words per sentence; (c) syllables per word; (d) type token ratio; (e) percent of words appearing among the 3000 most frequently occurring words in written English; (f) reading ease; and (g) grade level. Percent of words appearing among the 3,000 most frequently occurring words in written English was determined using search tools at https://www.wordandphrase.info/analyzeText.asp. The remaining metrics were determined using SEO Scout tools at https://seoscout.com/tools/text-analyzer. Use of both sets of online tools required that the text be formatted in particular ways to ensure accuracy and consistency. Specifically, hyphens were deleted so that COVID-19 would be treated as a single word. In addition, text had to be entered as a

single paragraph, with all text in lowercase and all punctuation removed to determine the percent of words appearing among the 3,000 most frequently used words in written English.

When taken together, the first ten source documents from the CDC had 12,654 words with an average readability of 8.4 (+ 2.3) grade level as determined by the SEO Scout site using a combination of the Flesch Kincaid reading ease algorithm, supplemented with the SMOG index, Automated Readability Index, Gunning Fog, and Coleman Liau scores (see https://seoscout.com/tools/text-analyzer for more). After being simplified following the MTC Guidelines to convey only the information deemed pertinent to the target population, the ten simplified documents had 4,657 words with an average readability of 2.4 (+ 0.5) grade level. Table 2 displays the average metrics for the first ten documents in their original and simplified forms.

Table 2: Average Metrics for the Ten Original and Simplified Documents

Metric	Original Mean (*SD*)	Simplified Mean (*SD*)
Total Words[1]	1265 (1034)	466 (262)
Average Number of Words per Sentence[1]	14.1 (3.4)	6.7 (1.3)
Average Number of Syllables per Word[1]	1.6 (0.14)	1.3 (0.06)
Type Token Ratio (Unique Words/Total Words)[1]	37% (12%)	31% (8%)
Percent of Words among 3,000 Most Frequent[2]	84% (6%)	90% (3%)
Flesh Kincaid Reading Ease[1]	60% (12%)	89% (4%)
Grade Level Equivalent on Readability Index[1]	8.4 (2.3)	2.4 (0.5)

[1]Metric generated at https://seoscout.com/tools/text-analyzer

[2]Metric generated at https://www.wordandphrase.info/analyzeText.asp

OUTCOMES AND BENEFITS

The immediate outcomes of our efforts include a set of 25 documents that are fully accessible to individuals with intellectual and developmental disabilities and others who read and listen with comprehension below a third-grade level. In the long term, we anticipate that our efforts to create the MTC Guidelines will lead to several new lines of inquiry and product development that will have positive outcomes and benefits for the target audience. These include (a) open-source tools for supporting stakeholders in producing texts that are consistently compliant with the MTC guidelines; (b) research regarding the ways that people with intellectual and developmental disabilities interact with and use texts created using the MTC Guidelines; and (c) research regarding the ways that features of text complexity might be manipulated in order to better support comprehension and literacy learning for children and adults with various profiles and needs. By increasing capacity to produce texts following the MTC Guidelines, while conducting investigations of useability, we hope that in the long term these guidelines increase opportunities for individuals with intellectual and developmental disabilities and others with extremely low literacy to independently access a myriad of texts regarding public health, emergency response, and emergency preparedness. This would have implications for spreading information, facilitating learning, increasing autonomy in decision making, and improving health outcomes for the target population.

DISCUSSION

Difficulties reading or listening to text with comprehension contribute to significant disparities in access to public health information and resulting health outcomes. With empirical evidence that adults with intellectual and developmental disabilities are up to eight times more likely to die after contracting COVID-19 (Gleason et al., 2021; Rabin, 2020), providing accessible information about protecting oneself and others remains of paramount importance. The need for this accessible information was recognized by the CDC and the CDC-F in the spring of 2020, early in the COVID-19 pandemic. The organizations responded by contracting with the Center for Inclusive Design and Innovation and the CLDS to create accessible versions of the CDC COVID-19 guidance documents. After the rapid review of the literature described here failed to reveal existing guidelines that could support the development of documents that would be accessible to people with intellectual and developmental disabilities who read and listen with comprehension at a third-grade level or lower, a new set of guidelines was created. The resulting research-based MTC Guidelines extracted information from the literature that was reviewed during the rapid review.

When the MTC Guidelines were applied to the original CDC COVID-19 guidance documents, the resulting documents were far less complex across all metrics. The simplified documents are significantly shorter, include sentences that are less complex and use more high-frequency words, and demonstrate high levels of consistency as demonstrated by comparison with the original documents and the standard deviations across metrics. Although the metrics suggest that the simplified documents will be easier to read, there is a need to evaluate the extent to which these documents can be read and understood by adults with intellectual and development disabilities who read at or below a third-grade level. Research is also needed to investigate whether reading these documents helps adults in the target population adopt practices to stay safe from COVID-19. Similarly, future research should also investigate how the MTC Guidelines might be used to improve access to other health and disaster preparedness information that is relevant to the target population.

We are encouraged by the success of the MTC guidelines to produce consistently less complex text because perceived difficulty has been shown to impact whether or not a text is read (Velayo, 1993). Both the metrics and side-by-side visual comparison of the two sets of documents suggest that the MTC documents will be perceived as easier to read. However, future research is needed to understand how the target population perceives the difficulty of the guidance documents. We are hopeful that people will return to the CDC for guidance in the future if they are able to have consistent and repeated opportunities to retrieve texts that they can read with comprehension. This is important because previous experience with, exposure to, and awareness of information resources has been shown to improve knowledge uptake (Buljan et al., 2018). Furthermore, repeated reading of texts with high internal consistency likely increases comprehension for the target population (Allington et al., 2015). Therefore, future research should investigate whether individuals are more likely to return to the CDC guidance once they are aware of the simplified resources and have success reading COVID-19 documents.

While the final documents are highly consistent and compliant with the MTC guidelines, we did not achieve this consistency immediately. Rather, just as the literature predicted (Hadden, 2015), it took many passes back and forth between authors in order to achieve the best iterations of texts possible. The time and degree of familiarity with the guidelines that was required to successfully create the set of COVID-19 documents described here limits the scalability of the approach. As such, future research should investigate how to operationalize where possible and scale the use of the MTC Guidelines, including training protocols and materials for authors to support integration of the MTC guidelines and resulting simplified documents into the production of written materials. Furthermore, it should be explored whether the MTC Guidelines are sufficiently detailed for the creation of smart automation tools to support writers in efficiently producing texts and checking compliance with the guidelines. Pending the outcomes of these areas of future research and development, effective application of the MTC Guidelines offers potential to increase personal access to vital information across a broad range of life sectors for adults with intellectual and developmental disabilities and others who read and listen with comprehension at a third-grade level and lower.

DECLARATIONS

The findings and conclusions in this report are those of the author(s) and do 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 Literacy & Disability Studies, Department of Allied Health Sciences, University of North Carolina at Chapel Hill, and 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.

REFERENCES

Allington, R. L., McCuiston, K., & Billen, M. (2015). What research says about text complexity and learning to read. *Reading Teacher, 68*(7), 491–501. http://dx.doi.org/10.1002/trtr.1280

Anderson, R. C. (1996). Research foundations to support wide reading. In V. Greaney (Ed.), *Promoting reading in developing countries.* (pp. 55–77). International Reading Association.

Arya, D. J., Hiebert, E. H., & Pearson, P. D. (2011). The effects of syntactic and lexical complexity on the comprehension of elementary science texts. *International Electronic Journal of Elementary Education, 4*(1), 107–125. https://iejee.com/index.php/IEJEE/article/view/216/212

Beck, I. L., Perfetti, C. A., & McKeown, M. G. (1982). Effects of long-term vocabulary instruction on lexical access and reading comprehension. *Journal of Educational Psychology, 74*(4), 506–521. https://doi.org/10.1037/0022-0663.74.4.506

Benson-Goldberg, S., & Erickson, K. A. (2020). Graphic symbols: Improving or impeding comprehension of Communication Bill of Rights? *Assistive Technology Outcomes and Benefits, 14*(1), 1–18. https://www.atia.org/wp-content/uploads/2020/06/ATOB-V14-A1-Benson-GoldbergErickson.pdf

Buljan, I., Malički, M., Wager, E., Puljak, L., Hren, D., Kellie, F., West, H., Alfirević, Ž., & Marušić, A. (2018). No difference in knowledge obtained from infographic or plain language summary of a Cochrane systematic review: Three randomized controlled trials. *Journal of Clinical Epidemiology, 97*(1), 86–94. https://doi.org/10.1016/j.jclinepi.2017.12.003

Centers for Disease Control and Prevention. (2020). *Health equity considerations and racial and ethnic minority groups.* https://www.cdc.gov/coronavirus/2019-ncov/community/health-equity/race-ethnicity.html

Cunningham, J.W., Hiebert, E.H., & Mesmer, H.A., (2018). Investigating the validity of two widely used quantitative text tools. *Reading and Writing, 31*(4), 813–833. https://doi.org/10.1007/s11145-017-9815-4

Cunningham, J. W., Spadorcia, S. A., Erickson, K. A., Koppenhaver, D. A., Sturm, J., & Yoder, D. E. (2005). Investigating the instructional supportiveness of leveled texts. *Reading Research Quarterly, 40*(4), 410–427. https://doi.org/10.1598/RRQ.40.4.2

Department of Health (2010). *Making written information easier to understand for people with learning disabilities.* United Kingdom Department of Health. https://www.gov.uk/government/publications/making-written-information-easier-to-understand-for-people-with-learning-disabilities-guidance-for-people-who-commission-or-produce-easy-read-information-revised-edition-2010

DuBay, W. H. (2004). *The principles of readability.* Impact Information

Erickson, K. A., Benson-Goldberg, S., & Geist, L. (2020). *Minimized text complexity guidelines.* Center for Literacy and Disability Studies, University of North Carolina at Chapel Hill. https://www.med.unc.edu/ahs/clds/resources/

Erickson, K. A., Hatch, P., & Clendon, S. (2010). Literacy, assistive technology, and students with significant disabilities. *Focus on Exceptional Children, 42*(5), 1–16. https://doi.org/10.17161/foec.v42i5.6904

Filippatou, D., & Pumfrey, P. D. (2006). Pictures, titles, reading accuracy and reading comprehension: A research review (1973-95). *Educational Research, 38*(3), 259–291. https://doi.org/10.1080/0013188960380302

Fisher, D., & Frey, N. (2014). Understanding and teaching complex texts. *Childhood Education, 90*(4), 306–313. https://doi.org/10.1080/00094056.2014.937290

Gleason, J., Ross, W., Fossi, A., Blonsky, H., Tobias, J., & Stephens, M. (2021). The devastating impact of Covid-19 on individuals with intellectual disabilities in the United States. *NEJM Catalyst.* https://catalyst.nejm.org/doi/full/10.1056/CAT.21.0051

Graesser, A. C., McNamara, D. S., Louwerse, M. M., & Zhiqiang, C. (2004). Coh-Metrix: Analysis of text on cohesion and language. *Behavior Research Methods, Instruments, & Computers, 36*(2), 193–202. https://doi.org/10.3758/BF03195564

Hadden, K. B. (2015). Health literacy training for health professions students. *Patient Education & Counseling, 98*(7), 918–920. https://doi.org/10.1016/j.pec.2015.03.016

Hadden, K. B., Prince, L. Y., Moore, T. D., James, L. P., Holland, J. R., & Trudeau, C. R. (2017). Improving readability of informed consents for research at an academic medical institution. *Journal of Clinical and Translational Science, 1*(6), 361–365. https://doi.org/10.1017/cts.2017.312

Hegerty, M., Carpenter, P. A., & Just, M. A. (1991). Diagrams in the comprehension of scientific texts. In R. Barr, M. L. Kamil, P. B. Mosenthal, & P. D. Pearson (Eds.), *Handbook of reading research, Vol. 2* (pp. 641–668). Lawrence Erlbaum Associates, Inc.

Hiebert, E. H. (2011). Beyond single readability measures: Using multiple sources of information in establishing text complexity. *Journal of Education, 191*(2), 33–42. https://doi.org/10.1177/002205741119100206

Hiebert, E. H. (2014, January). *Knowing what's complex and what's not: Guidelines for teachers in establishing text complexity.* TextProject, Inc. https://textproject.org/wp-content/uploads/papers/Hiebert-2014-Knowing-whats-complex-and-whats-not.pdf

Houts, P. S., Doak, C. C., Doak, L. G., & Loscalzo, J. (2006). The role of pictures in improving health communication: A review of research on attention, comprehension, recall, and adherence. *Patient Education and Counseling, 61*(2), 173–190. https://doi.org/10.1016/j.pec.2005.05.004

Hurtado, B., Jones, L., & Burniston, F. (2014). Is easy read information really easier to read? *Journal of Intellectual Disability Research, 58*(9), 833–829. https://doi.org/10.1111/jir.12097

Johnson, J. (1985). *Adults in crisis: Illiteracy in America.* National Institute on Education. https://files.eric.ed.gov/fulltext/ED254755.pdf

Krieger, J. L., Neil, J. M., Strekalova, Y. A., & Sarge, M. A. (2017). Linguistic strategies for improving informed consent in clinical trials among low health literacy patients. *Journal of the National Cancer Institute, 109*(3), 1–7. https://doi.org/10.1093/jnci/djw233

Leroy, G., Endicott, J. E., Kauchak, D., Mouradi, O., & Just, M. (2013). User evaluation of the effects of a text simplification algorithm using term familiarity on perception, understanding, learning, and information retention. *Journal of Medical Internet Research, 15*(7), 1–14. https://doi.org/10.2196/jmir.2569

Lesgold, A. M., & Welch-Ross, M. (2012). *Improving adult literacy instruction: Options for practice and research.* National Academic Press. https://doi.org/10.17226/13242

McNamara, D. S., Kintsch, E., Songer, N. B., & Kintsch, W. (1996). Are good texts always better? Interactions of text coherence, background knowledge, and levels of understanding in learning from text. *Cognition and Instruction, 14*(1), 1–43. https://doi.org/10.1207/s1532690xci1401_1

Mesmer, H. A., Cunningham, J. W., & Hiebert, E. H. (2012). Toward a theoretical model of text complexity for the early grades: Learning from the past, anticipating the future. *Reading Research Quarterly, 47*(3), 235–258. https://doi.org/10.1002/RRQ.019

Miles, K. S., & Cottle, J. L. (2011). Beyond plain language: A learner-centered approach to pattern jury instructions. *Technical Communication Quarterly, 20*(1), 92–112. https://doi.org/10.1080/10572252.2011.528345

Nomura, M., Nielsen, G. S., & Tronbacke, B. (2010). *Guidelines for easy-to-read materials, IFLA professional reports, No. 120.* The Hague: International Federation of Library Associations and Institutions. https://www.ifla.org/files/assets/hq/publications/professional-report/120.pdf

Office for Disability Issues. (2018). *Accessible communication formats.* https://www.gov.uk/government/publications/inclusive-communication/accessible-communication-formats

Parson, S., & Sherwood, G. (2015). A pilot evaluation of symbol-based information in police custody. *British Journal of Learning Disabilities, 44*(3), 213–224. https://doi.org/10.1111/bld.12140

Plain Writing Act of 2010, Pub. L. No. 111-274, 124 Stat. 2861 (2010).

Poncelas, A., & Murphy, G. (2007). Accessible information for people with intellectual disabilities: Do symbols really help? *Journal of Applies Research in Intellectual Disabilities, 20*(5), 466–474. https://doi.org/10.1111/j.1468-3148.2006.00334.x

Rabin, R. C. (2020). Developmental disabilities heighten risk of Covid death. *The New York Times.* https://www.nytimes.com/2020/11/10/health/covid-developmental-disabilities.html?campaignId=9HJ8Q

Reichle, E. D., Carpenter, P. A., & Just, M. A. (2000). The neural bases of strategy and skill in sentence–picture verification. *Cognitive Psychology, 40*(4), 261–295. https://doi.org/10.1006/cogp.2000.0733

Samuels, S. J. (1967). Effects of pictures on learning to read, comprehension and attitudes. *Review of Educational Research, 40*(3), 397–407. https://doi.org/10.3102/00346543040003397

Schuster, J., & Erickson, K. A. (2014). *Text complexity in the Dynamic Learning Maps™ Alternate Assessment System* (White Paper No. 14-01). University of Kansas Center for Educational Testing and Evaluation. https://dynamiclearningmaps.org/sites/default/files/documents/publication/text_complexity_in_the_Dynamic_Learning_Maps_alternate_assessment_system.pdf

Treptow, M. A., Burns, M. K., & McComas, J. J. (2007). Reading at frustration, instructional, and independent levels: The effects on students' reading comprehension and time on task. *School Psychology Review, 36*(1), 159–166. https://doi.org/10.1080/02796015.2007.12087958

Tricco, A. C., Langlois, E., Straus, S. E., & World Health Organization. (2017). *Rapid reviews to strengthen health policy and systems: A practical guide.* World Health Organization. https://www.who.int/alliance-hpsr/resources/publications/rapid-review-guide/en/

UNESCO. (2005). *EFA global monitoring report: Literacy for life, 2006.* Author. https://en.unesco.org/gem-report/report/2006/literacy-life

Velayo, R. S. (1993). Retention of content as a function of presentation mode and perceived difficulty. *Reading Improvement, 30*(4), 216–227.

Wagner, M., Newman, L., Cameto, R., & Levine, P. (2006). *The academic achievement and functional performance of youth with disabilities. A Report from the National Longitudinal Transition Study-2 (NLTS2).* (NCSER 2006-3000). SRI International. https://files.eric.ed.gov/fulltext/ED494936.pdf

Assistive Technology Outcomes and Benefits
Volume 16 Issue 2, Summer 2022, pp. 16-44
 ISSN 1938-7261
Available online: www.atia.org/atob

Voices from Academia

A Needs Assessment of COVID-19 Guidance for Adults with Developmental Disabilities

Ben Satterfield, Ed.D. and Zerrin Ondin, Ph.D.

Center for Inclusive Design and Innovation
College of Design
Georgia Institute of Technology

Corresponding Author
Dr. Ben Satterfield
Center for Inclusive Design and Innovation
College of Design, Georgia Institute of Technology
512 Means Street
Suite 250
Atlanta, GA 30318
Phone: (404) 618-3414
Email: rsatterfield8@gatech.edu

ABSTRACT

People with intellectual and developmental disabilities (IDD) have been identified as particularly vulnerable to the COVID-19 virus. Besides susceptibility to viral threats, adults with IDD often find it difficult to make the changes in behavior and routine that are necessary to minimize risks of exposure and infection. The Centers for Disease Control and Prevention (CDC) is concerned that individuals with developmental disabilities receive vital guidance in a format they could understand. The CDC engaged the team at Georgia Tools for Life at the Center for Inclusive Design and Innovation at Georgia Tech to conduct a rapid assessment as to whether current CDC guidance addressed the unique communication differences that such individuals may require and to suggest ways to improve this communication.

A Rapid Needs Assessment study was conducted that involved interviews with six adults with IDD. These sessions asked them to interact with CDC's COVID-19 materials. The team collected feedback on ease

of reading, comprehension ability, formatting, and use of images. In addition, a set of group interviews with four care providers was completed, collecting feedback on the same issues and materials.

When shown a CDC COVID-19 webpage, individual participants with IDD reported having difficulties reading and understanding the content due to unfamiliar vocabulary, lengthy and complex sentences, and dense text. Both caregivers and individuals with IDD suggested that documents should present simpler words and less text and raised questions regarding the effectiveness of use of images in such guidance. Individual comments helped researchers shape recommendations for production of more appropriate documents.

Keywords: intellectual disability, developmental disability, COVID-19

A NEEDS ASSESSMENT OF COVID-19 GUIDANCE FOR ADULTS WITH DEVELOPMENTAL DISABILITIES

The National Assessment of Adult Literacy (NAAL) suggests that more than 56 million adults in the United States read at levels below what is considered basic reading ability (White 2003). Lesgold and Welch-Ross (2012) assert that there has been little improvement in recent years. Comprehension of reading remains the area of poorest academic performance for virtually all adults with disabilities. This is most pronounced among adults with IDD (Wagner et al., 2006). Studies suggest that by middle school, the reading skills of students with intellectual disabilities stabilize at levels below a 3rd grade reading ability (Schulte et al., 2016). Nash, Clark and Karvonen (2016) suggest that only 20% of this group can read with comprehension at any level. Assistive Technology (AT) has been used with individuals with IDD to help them manage reading tasks in the context of school, workplace, and daily living (Davies et al., 2001; Lee et al., 2011; Wehmeyer et al., 2004).

The efficacy of AT use is linked to accessibility in the context of internet activity— particularly for people with IDD. The Web Content Accessibility Guidelines (WCAG 2.0, 2008) rests upon four central principles of accessibility: Web applications should be perceivable, operable, understandable, and robust. Of particular importance to individuals with IDD is the principle of being “understandable.” This suggests that the readability of text and the efficacy of images and other visual presentation is central to a reader’s ability to derive meaning from the content of the site or the app (Bunning et al., 2010).

While technology use has become more prevalent within society, challenges accessing content persist for people with IDD (Agren et al. 2020; Alper & Goggin, 2017; Chadwick et al., 2013; Clark, 2020; Karreman et al., 2007). Individuals with disabilities can use AT devices and supports to get on the internet and navigate to a site. However, if the content is not “understandable” then an impediment has been created and the individual’s right to accessibility has not been fully addressed (Agren et al, 2020; Bunning et al., 2010; Chadwick, 2013; Ellcessor, 2015; Lazar et al., 2015). Greg Vanderheiden (2008) observed that true accessibility would be within our reach when we exchange our emphasis on trying to “provide access to the interface” for a focus on “providing access to the underlying function” (p.6).

The well-being of persons with IDD could be at risk if guidance pertaining to the COVID-19 virus was not received and applied effectively. As the pandemic unfolded in 2020, the Centers for Disease Control and Prevention (CDC) took special concern that their guidance would be properly understood, and acted upon, by people with IDD, their families, and their care providers. The CDC had set a goal to provide information about COVID-19 in a format that followed the Plain Language guidelines (Plain Language Action and Information Network, 2011). Research suggests that Plain Language guidelines do not result in text that is simple enough to meet the needs of the entire population of adults with very low literacy skills, especially individuals with intellectual and developmental disabilities (Leroy et al., 2013). With regard to written instructions and guidance pertaining to health and safety, advice that is presented in language that is too complex for the intended audience is unlikely to be understood or followed.

As the COVID-19 pandemic unfolded, the CDC became concerned that individuals with IDD receive and apply its guidance effectively. The nature of the guidance itself had become complex and difficult to simplify. It was with a sense of urgency that the CDC reached out to Georgia Tools for Life (GATFL) at the Center for Inclusive Design and Innovation at Georgia Tech. GATFL was asked to conduct a rapid assessment of current CDC guidance to determine whether it addressed the unique communication differences that such individuals may require and to suggest ways to improve this communication.

GATFL is the Assistive Technology Act (1988) agency for the state of Georgia and had partnered with the CDC Foundation on training projects in the past. GATFL is staffed by people with extensive experience in working with people with IDD and has many relationships with public and private agencies that the CDC believed could be leveraged to draw together a group of individuals with IDD swiftly for this purpose.

TARGET AUDIENCE AND RELEVANCE

The target audience for this paper includes those who support and care for individuals with intellectual and developmental disabilities: their care providers, families, and friends. It also includes the employers, therapists, teachers and administrators, transition coordinators, vocational rehabilitation counselors, and support coordinators who work with them. Clearly there are significant threats to health and safety wrapped up in our responses to the COVID-19 virus, so individuals with IDD should benefit from the application of these findings. Anyone who can and does help shape the behaviors and understanding of these individuals will benefit from reading and considering the lessons learned here.

LITERATURE REVIEW

People with intellectual and developmental disabilities (IDD) have been identified internationally as one of the most vulnerable segments of the population with regard to viral infections such as COVID-19 (Buono et al., 2021). Overall, disorders of the respiratory system have been considered one of the chief threats to health and longevity for individuals with IDD (O'Leary et al., 2018; Truesdale et al., 2021). This

is particularly true of individuals with Down syndrome (O'Leary et al., 2018). Further, challenges related to intellectual disability, specifically the limited capacity to discern threats and evaluate risks, further exposes this group to dangerous complications (Biswas et al., 2010; Perera et al., 2020). These vulnerabilities have been brought into international focus in 2020 during the COVID-19 pandemic (Buono et al., 2021; Courtenay, 2020; Courtenay & Perera, 2020; Perera et al., 2020).

Heightened attention to the need for changes in behavior and observance of safety practices such as social distancing, frequent and thorough handwashing, and wearing facial coverings was considered especially significant for individuals with IDD. Health officials viewed minimizing risks by drawing attention to these safety practices as a priority for this group (Buono et al., 2021). The CDC was especially concerned for the safety of these individuals and sought ways to present its COVID-19 guidance most effectively. The CDC partnered with Georgia Tools for Life (GATFL) at the Center for Inclusive Design and Innovation (CIDI) at Georgia Tech to explore ways to make its guidance more accessible to people with disabilities including individuals who are blind (through Braille documents), have hearing impairments (via ASL videos), and those with IDD (through easy-to-read documents and videos).

The number of individuals with IDD in the United States is estimated to be between 2.6 and 4 million (Landes et al., 2020). IDD is comprised of a number of disabilities that affect an individuals' capacity in the areas of motor, communication, cognition, and behavior, and is lifelong in nature (Zablotsky et al., 2019). These disabilities include Down syndrome, cerebral palsy, and spina bifida, as well as less common disorders such as Fragile X.

Historically, the roles individuals from this group have played in the workforce would place them in such settings as warehouses, food service, supermarkets, and janitorial services (Hiersteiner et al., 2018). This suggests that a number of people with IDD have served in roles as essential workers in the early days of the pandemic (Thompson & Nygren, 2020).

Individuals with IDD have been found to experience poorer health outcomes than the general population (Buono et al., 2021; Helmsley & Balandin, 2014). Many individuals in this group are susceptible to infections which affect breathing and experience respiratory distress more often and for longer periods than the general population (Axmon et al., 2017; Chang et al., 2017). Adults with IDD who live in group home settings were found to be in greater jeopardy of exposure to, and mortality from, COVID-19 (Landes et al., 2020). Thus, for medical reasons and because these individuals were positioned for increased risk of exposure to COVID-19, it was important to provide guidance on health and safety procedures to this vulnerable segment of the population.

METHODS

Rapid Needs Assessment

The GATFL research team conducted remote (online) interviews with participants with IDD. The sessions made use of Georgia Tech's approved WebEx platform for these sessions. A semi-structured interview protocol was developed that focused on CDC's existing COVID-19 content and users' experiences and

needs. The interview questions are included in the appendix. Each participant with IDD joined the session with a parent who was their primary care provider. The sessions lasted around 50 minutes and were video recorded for later analysis.

The research team also conducted two group interview sessions with caregivers of adults with IDD including a total of four participants. A semi-structured protocol was also developed for the caregiver group interviews that focused on CDC's existing COVID-19 content and explored the participants' observations of the individuals for whom they provided care and their insights regarding what was effective and what was not. The questions are included in the appendix. The sessions lasted around 60 minutes and used the Georgia Tech WebEx online meeting platform. Sessions were video recorded for later analysis.

Development of Data Collection Protocols

Interview Protocol

An interview protocol was developed for the people with IDD, aiming to gather information about their experiences with CDC's COVID-19 information that is available through CDC's website, social media platforms, and printed media (such as flyers and posters).

The interview protocol consisted of three sections: (1) general information about the user, (2) questions for participants who previously used CDC's website for COVID-19 related information, and (3) questions for participants who have never used CDC's website for COVID-19 related information or participants who do not remember if they used CDC's website for COVID-19 related information.

General information about the user section includes five questions to understand participants' daily internet usage, AT that participants use to access the internet and computer, participants' experiences with CDC's website, social media platforms, and printed media.

Questions for participants who previously used CDC's website for COVID-19 related information section includes 17 questions to investigate participants' experiences with CDC's website, social media platforms, and printed media. Frequency of usage, information-seeking behavior, accessibility challenges faced, and alternative modalities preferred were asked in this section. These questions were planned to be asked to participants with previous experiences with the CDC's platforms and media.

Questions for participants who have never used CDC's website for COVID-19 related information or participants who do not remember if they used CDC's website for COVID-19 related information section includes 16 questions to investigate COVID-19 information resources used by participants and their evaluation of the CDC's website. These questions were planned to be asked to participants without previous experiences with the CDC's platforms and media.

The interview protocol was developed collaboratively by the research team at the Center for Inclusive Design and Innovation at Georgia Tech which included the authors of this article. The research team aimed to understand experiences of people with IDD with COVID-19 information resources and

preferences they have for the alternative media modalities. CDC conducted the final evaluation of the interview protocol to make sure it serves the project's mission.

The project team decided to individually interview people with IDD to understand their unique experience in sufficient detail and prevent peer influence that could potentially occur in a focus group setting.

Focus Group Protocol

A focus group protocol was developed for the primary care providers of people with IDD, aiming to gather information about their observations of the individuals for whom they provided care. The focus group protocol consisted of the same three sections and questions as the Interview Protocol. The questions were slightly revised to target the primary care providers' observations. CDC conducted the final evaluation of the focus group protocol to make sure it served the project's mission.

The project team decided to include the primary care providers of the individuals with IDD in order to supplement the data collected from the interviews. The same questions were asked to confirm insights obtained through individual interviews. We chose to conduct a focus group with the care providers as we expected the discussion among them to reveal valuable insight.

Recruitment

The research team recruited participants for individual interviews within the state of Georgia using invitation emails. To expedite this process, the research team reached out to agencies and organizations that served adults with IDD and specifically to leaders who would be familiar with individuals' reading levels. These leaders passed word of our study to individuals who met the study criteria. Individuals signed up through an online portal where consent was secured.

Participants for the caregiver group interviews were also recruited from within the state of Georgia using invitation emails. All four of the group interview participants were family members or primary care providers of adults with IDD who took part in the survey. The participating caregivers signed up through an online portal where consent to participate was secured.

Demographics

The team interviewed six adults with IDD. All of the interview participants met the following criteria: 1) they were 18 years and older, (2) they had an intellectual, developmental, or cognitive disability or a linguistic impairment, (3) they could read in English, and (4) they were currently living in, and present in, the United States. Among those who responded to our invitations there were two male participants and four female participants. Two participants were between the ages of 18–24. Four participants were between the ages of 25 and 34.

The caregiver group interview consisted of four adult care providers. Each care provider was the parent of an individual with IDD. All of the caregiver group interview participants were female. All met the following criteria: (1) they were 18 years and older, (2) they were caregivers of individuals with intellectual, developmental, or cognitive disability or linguistic impairments, (3) they could read in English, and (4)

they were currently living in and present in the United States.

As the need for this study was time-sensitive, the research team decided to move forward with the study once the number of participating adults with IDD passed five. Neilsen (2000) suggests that a five-member panel is sufficient for user experience focus groups.

Data Analysis

The recorded interviews were transcribed using Webex's automated captioning capabilities. Captioning files for the sessions were then manually reviewed and revised by the authors to ensure accuracy.

Transcripts from the interview sessions were combined and analyzed together to identify patterns and connections. Transcripts from the focus group sessions were analyzed to identify themes. Results were discussed for each question asked.

INDIVIDUAL INTERVIEW RESULTS

The individual interviews followed a semi-structured interview protocol that addressed several topics including: internet activity and assistive technology (AT) usage, experiences with CDC websites and social media platforms, and experiences with CDC printed materials (flyers and posters; see Figure 1). Then participants were instructed to read and examine a webpage from a CDC COVID-19 guidance site. Information was gathered regarding general impressions, readability and accessibility.

Figure 1: Examples of CDC Flyers and Poster

Internet Activity and Assistive Technology Usage

Each of the participants reported having an iPad that they used as their primary tool to connect to the Internet. Three participants reported having computers (a Chromebook, a tablet computer, and a PC) and used them less frequently than their iPads. Only one participant reported having a smart phone.

Four of the participants used YouTube for listening to music videos. Only one participant reported having a Facebook account. None of the participants reported having an Instagram account. Two of the participants mentioned using the BrainPOP app (an educational website with short, animated movies targeted for students in grades K–12) on their iPad.

Five of the participants reported that they spend less than an hour on the internet daily, while one participant reported spending two hours daily. All of the participants reported having used the Zoom video meeting platform in other online meetings, and had some experience navigating virtual platforms.

Experience with CDC's Website and Social Media Platforms

None of the participants reported having used CDC's website or social media platforms to find information about COVID-19. Only one participant reported that she had heard about the CDC web site, but had never visited it. One participant stated that sometimes COVID-19 information comes up on Facebook or YouTube, but he was not interested and had never clicked on it.

Experience with CDC's Flyers and Posters

None of the participants reported having seen CDC's flyers on COVID-19. Two participants stated that they have seen CDC's COVID-19 posters; these were observed at an individual's workplace. Other posters were reportedly seen at grocery stores and at medical clinics—although the individuals were not sure if these were the CDC's posters. An example of CDC flyers and posters is presented in Figure 1.

Use of CDC's Digital Platforms

None of the participants reported using CDC's digital platforms. The section below presents the results for questions targeting participants who have not used CDC's digital platforms for seeking COVID-19 information.

Frequency

Only one participant reported having searched for COVID-19 information. She had a weather app on her iPad and it has a link for COVID-19 statistics (new cases, deaths, etc.). The individual checked it every day as her coach told her that her Special Olympics Softball team might resume practices if the numbers came down. The other 5 participants responded that they do not search for news about COVID-19. One participant expressed that he watches COVID-19 information on TV if it comes up, but does not seek it out.

Resources and Platforms Utilized

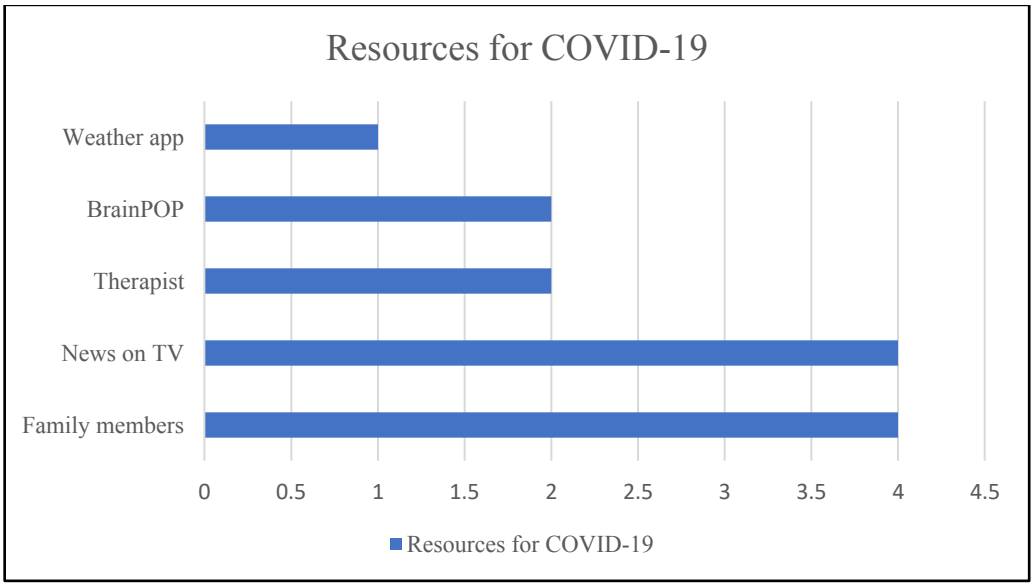
Four of the participants reported having learned about COVID-19 from their family members. Of these

four, two participants mentioned that their therapists talked with them about COVID-19. Two reported having experienced family members becoming sick and going through quarantine with COVID-19.

Four of the participants expressed that they have seen COVID-19 news on TV. Two participants mentioned that they have seen COVID-19 videos on the BrainPOP app. One participant said, as stated earlier, that she looked at her weather app on her iPad for COVID-19 statistics. The same participant reported having seen posters and having conversations at their workplace about COVID-19.

Distribution of the resources used for COVID-19 information by number of participants can be seen in Figure 2.

Figure 2: Resources for COVID-19



Types of Information

Only one participant reported having happened upon any COVID-19 information while using a digital platform. She reported using the weather app to learn about COVID-19 statistics and returned to this site later for updates. The other five participants reported that they had not searched for any COVID-19 information on any digital platform including that of the CDC. Only one participant expressed that they knew CDC had a website. None of the participants had ever visited it.

Experience with "How to Wear Masks" Page

During the interview, participants were asked to visit a CDC webpage about face masks (https://www.cdc.gov/coronavirus/2in this 019-ncov/prevent-getting-sick/how-to-wear-cloth-face-coverings.html). All of the participants visited the website and read the page aloud. Their responses to the questions are presented in the section that follows.

Initial Impressions

Participants reported having found the page difficult to read. Participants commented, “This is boring” and “There is [*sic*] a lot of words here.” Another participant said she already knew about masks, and there was no information in the page that was new. Four of the participants specifically mentioned having difficulties understanding the sentence which read: *“CDC does not recommend use of masks or cloth masks for source control if they have an exhalation valve or vent.”* They said they did not understand the words exhalation, valve, and vent. Two participants reported that they did not understand the word “incapacitated.” One participant stated that they did not understand the word “symptoms.”

All of the participants liked the pictures on the page (see images in Figure 3). When probed further on the pictures, participants said, “They were nice,” or “They were funny.” When asked about what they saw, the participants appeared to miss the meaning of arrows, and the check marks and Xs within the images. One individual commented about the image that illustrated social distancing, saying, “I don’t think they like each other.” This suggested to the research team that these images did not contribute to understanding of the intended message.

Figure 3: Images from CDC “How to Wear Masks” Page

Three of the participants explored other areas of the CDC’s site after completing the reading. They said they clicked on the links at the bottom of the web page (under More Information). Two participants clicked on the *“ASL Video Series: Easy DIY Mask”* link. Another participant watched the ASL video for the *“Use of Cloth Face Coverings to Help Slow the Spread of COVID-19”*. Each of these participants said they enjoyed watching the video and suggested that they would watch something similar to this video to learn about COVID-19.

All of the participants reported having liked the pictures. Three of the participants reported having greatly liked the ASL video. One participant reported having disliked the difficult words. One participant commented that there are too many things on the page, and this made them "dizzy." None of the participants reported any difficulty navigating the page. Two participants observed that it was easy to get to the page and click on the items and links.

Other Ways to Present This Information More Clearly

When asked if there might be other ways to present this information that would help them better understand, two participants commented that it would be helpful if the page used simpler words. Another suggested using fewer words. Three of the participants stated that they would like to see pictures that helped them understand.

One participant reported that "videos would be good." He said that he did not understand the words *exhalation*, *valve*, or *vent* and he did not understand the differences between the mask types (surgical vs. others). He suggested that it would be helpful if someone explained this to them in a video. Another participant commented that she would learn more if the site had interactive activities like those on BrainPOP.

Preferences Around Text Simplification

In order to investigate the participants' preferences and to help identify the level of text complexity that would be appropriate for individuals with IDD, the following questions were asked: 1) Did you understand the words in this webpage? 2) Did you understand what the webpage was saying? 3) Would you like it if the webpage used words that are easier to understand?

Two participants said that they would like it if the webpage used words that are easier to understand. Four of the participants reported understanding what the webpage was saying. However, after follow-up questions, they all said that there were words that they did not understand. They mentioned the words: *exhalation*, *valve*, *vent*, *incapacitated*, and *infected*.

Future Usage of CDC's Website

After visiting the site, three participants said that they would come back to CDC's website for more information about COVID-19 in the future. Two participants said that they would not come back to CDC's website for information about COVID-19 in the future. Of these, one participant commented that they prefer BrainPOP (interactive activities vs. reading).

Preferences Around CDC Flyers

Two of the participants expressed that they would not read a COVID-19 flyer. Two of the participants stated that they would try to read a COVID-19 flyer and one of them suggested that they doubted that they would understand it fully. One of the participants expressed that they would like to see information on prevention in the workplace, specifically about social distancing at the workplace.

CAREGIVER GROUP INTERVIEW RESULTS

The research team also conducted online group interviews with caregivers of these participants as part of this study. Their responses and observations are recorded in the sections below.

Assistive Technology Usage

All panelists reported that the individuals with IDD they worked with do not use any assistive technology to access internet or to use a computer.

Experience with CDC's Website and Social Media Platforms

Participants reported that none of the individuals with IDD they represented have used CDC's website or social media platforms (YouTube, Facebook, Twitter, or Instagram) for COVID-19 related information. Two participants reported that individuals with IDD they care for do not use Facebook, while two reported infrequent use. One reported that her son uses Instagram. All of the participants stated that the individuals with IDD use YouTube mainly for watching movies and music videos. Two of the participants with IDD were reported to have email accounts, but they rarely send emails. One participant's daughter uses a weather app on her iPad that has a link for COVID-19 statistics (cases, death, etc.). She reportedly checks it every day.

Participants commented that the individuals with IDD they represented might be seeing CDC's COVID-19 information when they use YouTube (as an ad or link) but that they never clicked on these links.

Experience with CDC's Flyers and Posters

Participants reported that most of the individuals with IDD they represented had not seen any flyers from the CDC on COVID-19. One reported having seen CDC's posters on COVID-19 at grocery stores and at the gym. Those posters were about wearing masks. Another participant said her daughter had reported having seen CDC posters at her work in a restaurant.

Use of CDC's Digital Platforms

The panel said that none of the individuals with IDD had used any of CDC's digital platforms. The section below presents the results for questions targeting participants with IDD reported to have not used CDC's digital platforms for seeking COVID-19 information.

Frequency

Three participants stated that individuals with IDD they represented do not actively seek COVID-19 information utilizing any digital format. Instead, they are informed by their family members about COVID-19. One participant reported that her daughter checks COVID-19 statistics pretty much every day using a weather app installed on an iPad.

Resources and Platforms Utilized

All of the panelists reported that the individuals with IDD they represented have been informed about COVID-19 by their families. Two of the participants specifically mentioned that their individuals had watched news on TV and learned supplementary information about COVID-19. One participant mentioned that her daughter has also been informed about COVID-19 through training at her workplace. Another participant expressed that her daughter's therapist talks with her about COVID-19 frequently.

Types of Information

One participant's daughter was interested in when COVID-19 will be over so she can go on vacation or can see her friends again in person. Another participant's daughter was interested in COVID-19 statistics, as she was looking forward to the resumption of Special Olympics softball. Several panelists reported the individuals with IDD they provided care to had questions about self-quarantine practices, as well as precautions they can take, such as washing hands and covering coughs and sneezes to keep the germs away.

One participant's son was focused on what he needs to do in different situations (e.g., when does he need to wear a mask, how can he tell what the requirements of the situation or environment might be, etc.). Another explained that her daughter (who had been one of the participants in the individual interviews) experienced confusion about the purpose of wearing masks. The individual had commented that she thought masks were for protecting herself and not others.

Reasons Why CDC Platforms Have Not Been Used

All of the participants agreed that the individuals with IDD they represented do not conduct internet searches, but rather click on familiar links. None of the individuals reported actively seeking COVID-19 information online. So, they are not singling out CDC's website to avoid. Panelists also volunteered that the individuals with IDD they represented have not seen their parents visiting CDC's website so there was not a model in the house for this either. Another participant mentioned their daughter probably did not think about going to CDC's website. They added that their daughter probably heard about CDC in the TV news.

Experience with "How to Wear Masks" Page

During the caregiver group interviews, participants were asked to visit CDC's webpage providing guidance for wearing face masks (Centers for Disease Control and Prevention, 2020). Their answers to our questions are provided in the sections that follow.

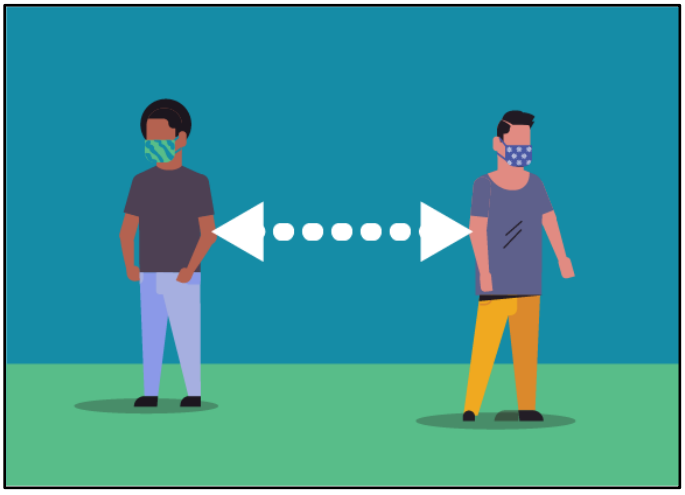
Initial Impressions

Panelists explained that it is laborious for individuals with IDD to read so much text. One stated that fonts used are not big enough for people who struggle with reading. One participant explained that their child would not understand the difference between masks mentioned in the following sentences: *"Do NOT use a mask meant for a healthcare worker. Currently, surgical masks and N95 respirators are critical supplies that should be reserved for healthcare workers and other first responders."* Another panelist commented

that CDC should explain the meanings of exhalation valve and vent instead of just using these words in the sentence without any further explanation.

The care provider panel discussed their observations that the pictures used on this page were not very helpful. One suggestion for improvement was to use the pictures to show what was said in the text such as showing the pictures of N-95 masks saying: “this is what it looks like.” One participant mentioned that images need to be more concrete, perhaps using real people instead of the illustrations. Another participant agreed on this comment.

Figure 4: Social Distancing Image



Another observation was made regarding the social distancing picture (see Figure 4 above) on this webpage. One participant posited that this picture may not convey what CDC is trying to say. Another panelist suggested to change the picture to show two people having their arms stretched out to both sides and still not touching each other (fingertips to fingertips). The other participants liked this suggestion. Three of the panelists agreed that the individuals with IDD would need more explanation or background information in order to understand how the pictures applied to the content on the page.

All of the participants agreed that the individuals with IDD they represented would enjoy and learn from a video. Two of the participants reported that their individuals had watched ASL videos for face masks (a link was provided at the bottom of the web page) during their interviews and liked them a lot. One participant suggested to have interactive features on the site such as a game, activities, or *“something that the individuals can click on.”* They added that would help their adult child learn better.

Preferred Features

One of the panelists observed that her daughter (who was one of the study participants) did not have any problem with the page about masks during her interview. She added that her adult child was very knowledgeable about the content. However, she asserted that her daughter’s experience with the site would be different if she did not already know so much about COVID-19. All of the participants discussed

that some sentences were complex and that vocabulary could be simplified. The vocabulary words specifically mentioned were *sanitizer*, *disinfect*, *exhalation valve*, and *vent*.

Another participant expressed concern that text supported by a picture may not have the intended effect for individuals with IDD. She added that length of the text and the vocabulary used in the text is crucial. For example, if the text includes new vocabulary, such as exhalation vent, that will cause a problem. She also suggested that the picture should directly support what the text says. Another participant commented on the layout of the page (text is on one side of the page and the picture is on the other side) and stated that if their adult child sees the picture in close proximity to the text she reads, it is much easier for her to absorb and understand.

Other Ways to Present Information More Clearly

Two participants suggested to have a *"speaker"* button for people with IDD to press to read the text on the webpage out loud. Other participants also liked the suggestion. Another panelist suggested having a button that produces a simpler version of the page when clicked.

One participant suggested making the site more interactive utilizing videos, games, and quizzes. That way, they added, "younger people with disabilities would stay longer on the site and get more information without realizing they are getting more information." All of the participants agreed that the individuals with IDD they represented would enjoy and learn from a video.

Preferences Around Simplified Text

The panel agreed that the text used was difficult and would be daunting for individuals with IDD to comprehend. One participant observed that there are a lot of words on the page and that would discourage their adult child from trying to read it. They also expressed that sometimes their adult child reads text and can pronounce all the words, but when they finish reading, they are unable to remember anything or answer questions about the text. The participant's suggestion was to provide a video together with the text, which they believed would work a lot better.

The care providers also commented on the importance of the dissemination. They expressed that these resources should be distributed to the specific groups in the community that serve individuals with disabilities. They added that people who might go over these resources with individuals with IDD (such as doctors, therapists, program coordinators, coaches, etc.) should be made aware that these resources are available. They also commented that there are other groups who can benefit from simpler text such as younger readers, ESL students and families, etc. Another participant suggested having a button to print the simpler version of the document on the website.

Preferences Around CDC Flyers and Posters

All of the participants agreed that the individuals with IDD they provided care to might look at posters but would probably not read them unless prompted. They added that the location of posters is important, since they are not going outside frequently at this time.

One participant explained that individuals with developmental disabilities tend to talk to a parent, caregiver, teacher, therapist, or someone who has some kind of authority for information, especially when it relates to COVID-19. The caregivers agreed that these people should be informed about CDC resources available with simplified text.

One participant stated that her daughter might try to read a simplified version of CDC's COVID-19 flyers. She added that her daughter needs to read any printed material several times before she understands it. Participants discussed whether or not the individuals with IDD would read CDC's COVID-19 articles when provided with a printed copy. They all agreed that they would probably not read them unless prompted by their parents.

One of the panelists commented that her son did not have any difficulty reading the page, but that was because he already knew about the content. She was curious to see what her son's reading performance would be with unfamiliar content.

Another parent commented that her daughter does not understand that pictures on the page are connected to the text on the page. As a result, she suggested pictures be located closer to the related content and added that maybe a little video would also be helpful.

SUMMARY AND DISCUSSIONS

Summary of Findings

When presented with CDC's web-based guidance on the "How to Wear Masks" page, the individual participants reported having difficulties reading and understanding the content. Unfamiliar vocabulary, lengthy and complex sentences, and dense text presented issues for the participants. More space between lines and larger fonts were also identified as ways to improve readability. The caregivers in the group interviews were unanimous in their assertion that the individual participants brought a great deal of background knowledge to their encounter with CDC's site. Without this prior learning, these participants would have had even greater difficulty comprehending the content.

Findings from the interviews also appear to suggest that images on the site did not clarify or inform. When asked about the images, the interview participants failed to identify the information the images were intended to convey. Researchers noted that the images were not contributing to comprehension. Caregiver group interview participants reported that the pictures were generally not instructive or helpful and lacked concrete detail that people with IDD require.

The caregivers agreed that less complex and less compact text would help individuals with IDD be able to read and comprehend the content. Panelists asserted that images needed to be more concrete, more closely aligned to the content, and placed in closer physical proximity to the content on the page in order to be of value for comprehension. The caregivers also suggested the inclusion of a button embedded on each page in the CDC site that would open a simpler version of CDC documents. The caregivers also encouraged dissemination of readable documents to the groups in the communities with which these

individuals associate, as people with IDD will seek information and clarification from authority figures they trust.

Discussion of Findings

It is clear from the literature that adults with IDD are a particularly vulnerable population relative to the COVID-19 virus. These individuals often live and work in situations where they may be at risk for exposure to COVID-19. Based upon their disability and their living and working circumstances, they are often poorly situated to assess risks and to adjust behavioral patterns that may increase their vulnerability. Hence, clear concrete practical health guidance is essential to help this group stay safe during a pandemic.

The CDC is to be commended for its care and concern that their messaging was effectively connecting with people with IDD. It would be a mistake to ignore or underestimate this group of adults regarding their capacity to learn and adopt healthy practices. These findings suggest that the individuals can and do make significant adjustments in their lifestyles to adopt safety and health practices. The CDC was wise to investigate the sources of their guidance. While this group was familiar with technology, it should be remembered that not all individuals with IDD have such experience or access.

While the individuals in this study demonstrated a pattern of technology use that was largely limited to familiar and preferred activities (music, movies, interactive activities, and games), it is worth noting that none of them or their care providers saw themselves as using “assistive” technology. All of the participants had demonstrated some level of comfort using consumer platforms like tablets, computers, Chromebooks, and cellphones. Further, it is noteworthy that these individuals had some level of social media activity—even if they did not seek out COVID-19 related information from it—and that all of the participants had experience with remote conferencing systems like Zoom. This suggests that such media and platforms *could* play a role in disseminating critical information to this population in the future if the message was communicated appropriately and individuals were aware of it.

Nonetheless, it was observed that none of our participants engaged in searches that involve typing URLs. Rather, these adults with IDD appeared to rely on the familiar and look to established sources of authority for guidance. Families and care providers had been their primary source of health information. The strategy that emerged from our panel to emphasize dissemination of easy-to-read documents to the leaders and groups in the community, as well as to adults with IDD, may prove to be especially valuable.

The findings of this study also make clear the need to simplify the guidance provided by health officials. The individuals with IDD and the care provider panelists were in agreement that written materials for this population needed a simplified, uncomplicated approach. Familiar words, uncomplicated sentences, well-spaced lines using slightly enlarged fonts, and which address focused, relevant topics, have all been identified as elements of an appropriate approach to creating documentation that is accessible for this group.

It was confusing to hear that our participants like images and want images included, but are unable to derive the intended meaning from the images presented. The literature does suggest, however, that

without proper instruction, images may actually distract from understanding of text. It seemed to the research team that our participants valued the aesthetic quality of having pictures.

CONCLUSIONS AND FUTURE STUDY

The results of the interviews with individuals with IDD suggest several considerations for language that is used to communicate information and guidance about COVID-19 to persons with IDD. First, such guidance needs to incorporate the following suggestions:

- Maintain a single, clear focus in each document
- Shorten sentences and avoid complex sentence structure
- Limit the amount of text on a page
- Increase the font size of the text that is presented
- Increase line spacing
- Reduce the complexity of vocabulary and use high-frequency words

Second, providing health and safety advice to individuals with IDD will require intentionality and care in the presentation of content, as well as thoughtful approaches to dissemination in order to have an impact on their lives. Thoughtful use of social media supported by consistent messaging from groups and leaders in local communities can help adults with IDD be aware of important health and safety information and be able to access and understand the content to be shared.

Third, images used in any such health and safety documentation need to be concrete and closely aligned to the content. Images should be placed in close physical proximity to the content on the page in order to be of value for comprehension. While the individuals appear to prefer images in documents they read, the research team does not believe that the images used have contributed to understanding. However, they may be providing aesthetic value, which the participants appreciated. Further examination of the use of images in such presentations is recommended.

Limitations

The findings regarding difficulty with complex text experience by adults with IDD are consistent with the lessons from the research literature. However, the user experience testing in this study was conducted as a rapid response to the CDC's immediate need for information. Only a single study was conducted, and that was done with a limited population. The findings may not be representative of all adults with IDD. As the pressure from the COVID-19 pandemic subsides, these interview protocols should be repeated with more geographically and culturally diverse populations to confirm the generalizability of the findings.

OUTCOMES AND BENEFITS

There are several outcomes and benefits from this study. This article describes the vulnerable nature of adults with IDD and their need for health and safety information that they can read and comprehend. This

is important for agencies to keep in mind when sharing the guidance and suggestions derived from scientists' and researchers' findings. The participants in this study have presented valuable insight into the complexity of currently available resources and have identified specific ways to simplify the content and presentation of such materials for consumption by adults with IDD. These findings will be particularly useful to those who care for and provide guidance to these individuals. Care providers, employers, therapists, and disability service professionals will find these suggestions helpful when selecting materials to share with their charges. These findings further support the research being done on Minimized Text Complexity (MTC) which is described in another article in this journal volume.

One care provider commented on the importance of having a simplified format available for her son. Her comment speaks to the greater desired outcome which lies beneath our collective efforts:

> *"Our hope is that our [individuals] will be independent one day. I am not going to be here forever. At some point my child may have to seek information on his own and develop skills to do that. He needs to have something available that he can understand whether he goes there by himself or not, because at some point, I want him to develop that skill."*

DECLARATIONS

The findings and conclusions in this report are those of the author(s) and do 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.

REFERENCES

Alfredsson Ågren, K., Kjellberg, A., & Hemmingsson, H. (2020). Access to and use of the Internet among adolescents and young adults with intellectual disabilities in everyday settings. *Journal of Intellectual & Developmental Disability*, *45*(1), 89–98. https://www.tandfonline.com/doi/pdf/10.3109/13668250.2018.1518898

Alper, M., & Goggin, G. (2017). Digital technology and rights in the lives of children with disabilities. *New Media & Society*, *19*(5), 726–740. https://journals.sagepub.com/doi/pdf/10.1177/1461444816686323

Axmon, A., Höglund, P., & Ahlström, G. (2017). Chronic respiratory disorders and their treatment among older people with intellectual disability and/or autism spectrum disorder in comparison with the general population. *Healthcare*, *5*(3), 40. https://doi.org/10.3390/healthcare5030040

Biswas, A. B., Vahabzadeh, A., Hobbs, T., & Healy, J. M. (2010). Obesity in people with learning disabilities: Possible causes and reduction interventions. *Nursing Times*, *106*(31), 16–18. https://pubmed.ncbi.nlm.nih.gov/20806643/

Boyle, C. (2012). Trends in the prevalence of developmental disabilities in US children, 1997-2008. *Pediatrics*, *127*(6), 1034–1042. https://www.cdc.gov/nchs/ppt/nchs2012/ss-22_blumberg.pdf

Bunning, K., Trapp, E., Seymour, K., Fowler, M., & Rollett, B. (2010). Survey of the linguistic accessibility of websites designed for people with intellectual disability. *Journal of Applied Linguistics & Professional Practice*, *7*(3), 297-316. https://doi.org/10.1558/japl.v7i3.297

Buono, S., Zingale, M., Città, S., Mongelli, V., Trubia, G., Mascali, G., Occhipinti, P., Pettinato, E., Ferri, R., Gagliano, C., & Greco, D. (2021). Clinical management of individuals with intellectual disability: The outbreak of COVID-19 pandemic as experienced in a clinical and research center. *Research in Developmental Disabilities*, *110*, 103856. https://doi.org/10.1016/j.ridd.2021.103856

Centers for Disease Control and Prevention (2020, September 10). How to wear masks. https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/how-to-wear-cloth-face-coverings.html

Chadwick, D., Wesson, C., & Fullwood, C. (2013). Internet access by people with intellectual disabilities: Inequalities and opportunities. *Future Internet*, *5*(3), 376–397. https://www.mdpi.com/1999-5903/5/3/376

Chang, C. K., Chen, C. Y., Broadbent, M., Stewart, R., & O'Hara, J. (2017). Hospital admissions for respiratory system diseases in adults with intellectual disabilities in southeast London: A register-based cohort study. *BMJ Open*, *7*, e014846. http://dx.doi.org/10.1136/bmjopen-2016-014846

Clark, J. (2021). A coordinated effort: Cultural and policy requirements for digital accessibility. *College & Undergraduate Libraries*, *27*(2–4), 265–280. https://www.tandfonline.com/doi/full/10.1080/10691316.2021.1932659

Courtenay, K. (2020). COVID-19: Challenges for people with intellectual disability. *British Medical Journal*, *369*, m1609. https://doi.org/10.1136/bmj.m1609

Courtenay, K., & Perera, B. (2020). COVID-19 and people with intellectual disability: Impacts of a pandemic. *Irish Journal of Psychological Medicine*, *37*(3), 231-236. https://www.cambridge.org/core/journals/irish-journal-of-psychological-medicine/article/covid19-and-people-with-intellectual-disability-impacts-of-a-pandemic/EE2156045429D885B49CBBBEBA5A96C5

Davies, D., Stock, S., & Wehmeyer, M. (2001). Enhancing independent internet access for individuals with mental retardation through use of a specialized web browser: a pilot study. *Education and Training in Retardation and Developmental Disabilities*, *36*(1), 107–113. https://www.jstor.org/stable/24481620

Fernando, H. F., & Botelho, F., (2021). Accessibility to digital technology: Virtual barriers, real opportunities. *Assistive Technology*, *33*(1), 27–34, https://www.tandfonline.com/doi/pdf/10.1080/10400435.2021.1945705

Freyhoff, G., Hess, G., Kerr, L., Menzel, E., Tronbacke, B., & Van Der Veken, K. (1998). *Make it simple: European guidelines for the production of easy-to-read information for people with learning disability*. ILSMH European Association.

Hemsley, B., & Balandin, S. (2014). A metasynthesis of patient-provider communication in hospital for patients with severe communication disabilities: Informing new translational research. *Augmentative and Alternative Communication*, *30*(4), 329–343. https://doi.org/10.3109/07434618.2014.955614

Hiersteiner, D., Butterworth, J., Bershadsky, J., & Bonardi, A. (2018). *Working in the community: The status and outcomes of people with intellectual and developmental disabilities in integrated employment—Update 3*. NCI Data Brief. Human Services https://www.nationalcoreindicators.org/upload/coreindicators/NCIEmployment_Update3_DataBrief.pdf

Karreman, J., Van der Geest, T., & Buursink, E. (2007). Accessible website content guidelines for users with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, *20*(6), 510–518. http://dx.doi.org/10.1111/j.1468-3148.2006.00353.x

Landes, S. D., Turk, M. A., Formica, M. K., McDonald, K. E., & Stevens, J. D. (2020). COVID-19 outcomes among people with intellectual and developmental disability living in residential group homes in New York State. *Disability Health Journal*, *13*(4), 100969. https://doi.org/10.1016/j.dhjo.2020.100969

Lee, Y., Wehmeyer, M., Palmer, S., Williams-Diehm, K., Davies, D., & Stock, S. (2011). The effect of student-directed transition planning with a computer-based reading support program on the self-determination of students with disabilities. *The Journal of Special Education*, *45*(2), 104–117. https://doi.org/10.1177/0022466909358916

Leroy, G., Endicott, J. E., Kauchak, D., Mouradi, O., & Just, M. (2013). User evaluation of the effects of a text simplification algorithm using term familiarity on perception, understanding, learning, and information retention. *Journal of Medical Internet Research*, *15*(7), 1–14. https://doi.org/10.2196/jmir.2569

Lesgold, A. M., & Welch-Ross, M. K. (Eds.). (2012). *Improving adult literacy instruction: Options for practice and research*. National Academies Press. https://www.nap.edu/catalog/13242/improving-adult-literacy-instruction-options-for-practice-and-research

Mencap. (2009). *Am I making myself clear? Mencap's guidelines for accessible writing*. Retrieved from http://www.mencap.org.uk/download/making_myself_clear.pdf

Nash, B., Clark, A.K., & Karvonen, M., (2016). *First contact survey: a census report on the characteristics of student eligible to take alternate assessments* [Technical Report #16-01]. University of Kansas, Center for Educational Testing and Evaluation. https://dynamiclearningmaps.org/sites/default/files/documents/publication/First_Contact_Census_2016.pdf

Neilsen, J. (March 2000). *User testing: why you only need to test with 5 users*. Neilsen Norman Group. https://www.nngroup.com/articles/why-you-only-need-to-test-with-5-users/

O'Leary, L., Cooper, S. A., & Hughes-McCormack, L. (2018). Early death and causes of death of people with intellectual disabilities: A systematic review. *Journal of Applied Research in Intellectual Disabilities*, *31*(3), 325–342. https://doi.org/10.1111/jar.12417

Perera, B., Audi, S., Solomou, S., Courtenay, K., & Ramsay, H. (2020). Mental and physical health conditions in people with intellectual disabilities: Comparing local and national data. *British Journal of Learning Disabilities*, *48*(1), 19–27. https://doi.org/10.1111/bld.12304

Plain Language Action and Information Network. (2011, March). *Federal plain language guidelines*. https://www.plainlanguage.gov/media/FederalPLGuidelines.pdf

Pomputius, A. (2020). Assistive technology and software to support accessibility. *Medical Reference Services Quarterly*, *39*(2), 203–210. https://doi.org/10.1080/02763869.2020.1744380

Schulte, A. C., Stevens, J. J., Elliott, S. N., Tindal, G., & Nese, J. F. T. (2016). Achievement gaps for students with disabilities: Stable, widening or narrowing on a state-wide reading comprehension test? *Journal of Educational Psychology*, *108*(7), 925–942. http://dx.doi.org/10.1037/edu0000107

Thompson, J. R., & Nygren, M. A. (2020). COVID-19 and the field of intellectual and developmental disabilities: Where have we been? Where do we go? *Intellectual and Developmental Disabilities*, *58*(4), 257–261. https://doi.org/10.1352/1934-9556-58.4.257

Truesdale, M., Melville, C., Barlow, F., Dunn, K., Henderson, A., Hughes-McCormack, L. A., McGarty, A., Rydzewska, E., Smith, G. S., Symonds, J., Jani, B., & Kinnear, D. (2021). Respiratory-associated deaths in people with intellectual disabilities: a systematic review and meta-analysis. *BMJ Open*, *11*(7), e043658. https://bmjopen.bmj.com/content/11/7/e043658.abstract

University of Minnesota. (2006). *Fog index*. Retrieved from: http://www.fdp.finop.umn.edu/groups/ppd/documents/information/writing_tips.cfm

Vanderheiden, G. C. (2008). Ubiquitous accessibility, common technology core, and micro assistive technology: Commentary on "computers and people with disabilities". *ACM Transactions on Accessible Computing (TACCESS)*, *1*(2), 1-7. https://doi.org/10.1145/1408760.1408764

Wagner, M., Newman, L., Cameto, R., & Levine, P. (2006). *The academic achievement and functional performance of youth with disabilities. A report from the national longitudinal transition study-2* (NLTS2). (NCSER 2006-3000). SRI International. https://files.eric.ed.gov/fulltext/ED494936.pdf

Wehmeyer, M. L., Smith, S. J., Palmer, S. B., & Davies, D. K. (2004). Technology use by students with intellectual disabilities: an overview. *Journal of Special Education Technology*, *19*(4), 7–21. https://doi.org/10.1177/016264340401900402

White, S. (2003). *The 2003 national assessment of adult literacy* (NCES 2003-495r). U.S. Department of Education, National Center for Education Statistics.

World Wide Web Consortium (W3C), (2022). *Web Content Accessibility Guidelines (WCAG) d 2.0*. Retrieved from http://www.w3.org/TR/WCAG20/

Zablotsky, B., Black, L., Maenner, M., Schieve, L., Danielson, M., Bitsko, R., Blumberg, S., Kogan, M., & Boyle, C. (2019). Prevalence and trends of developmental disabilities among children in the United States: 2009–2017. *Pediatrics*, *144*(4), e20190811. https://doi.org/10.1542/peds.2019-0811

APPENDIX

Individual Interview Questions

General Information About the User

1. Do you have any special tools to help you use your computer?
   Can you tell me about them?
   Do you use any special software to help find things on the internet?

2. Have you ever used the CDC's webpage to find information about COVID-19?
   Have you ever seen the CDC information about COVID-19 on Facebook? YouTube? Instagram? Twitter?
   (Yes/No question)

3. Have you ever read a paper from the CDC on COVID-19?
   (Yes/No question)

4. Have you ever seen or read a poster from the CDC on COVID-19?

*If the participant **has not previously used** the CDC's website or social media platforms for COVID-19 related information, ask questions from 5 to 21.*

*If the participant **has not used** the CDC's website or social media platforms for COVID-19 related information, ask questions from 22 to 37.*

5. Where do you go to get information from the CDC on COVID-19? CDC webpages? Facebook? Instagram? Twitter? Other?

6. Which of the places in [the] last question do you go to most often? Which do you go to second most often?

7. How many times a week do you look for information about COVID-19 from the CDC?

8. What do you search for when you go to the CDC for COVID-19 information? Can you give me some examples?

9. *(choose one example the participant mentioned)* Did you find what were you looking for in that webpage?
   (if the participants do not remember, let them visit the resources while answering the question)

10. How would you change that webpage to make it more helpful?

11. What did you like the best about that webpage?

12. What did you not like about that webpage?

13. Did you have any trouble reading the CDC's webpage?
    (wait for the answer; if participant says yes, ask the following probe)
    Tell me about the trouble you had.

14. What ways could the CDC use to present this information more clearly?

15. Did you understand the words on this webpage?
    Did you understand what the webpage was saying?
    Would you like it if the webpage used words that are easier to understand?

16. What information about COVID-19 would [you] like to see the CDC talk about?

17. What else would you like to tell me about how you have learned about COVID-19?

(if time permits, ask the questions below; if not, skip them)

18. Would you read the CDC information about COVID-19 if you could get it printed on paper?
    (wait for the answer, then ask the following probe)
    Can you tell me why?

19. What COVID-19 information would you like to see on a paper?

20. Would you read the CDC information about COVID-19 if you could get it on a poster?
    (wait for the answer; then ask the following probe)
    Can you tell me why?

21. What COVID-19 information would you like to see on a poster?

(thank the participant and conclude the sessions)

22. How often do you search for COVID-19 related information?

23. Where do you go to get information about COVID-19?
    Google search? Facebook? Instagram? Twitter? Friends and family?
    Papers?
    Posters?
    Organizations?

24. Which one of the sites/sources in the question above do you use most?
    Second most?
    Third?

25. What kinds of information about COVID-19 do you search for?
    Can you give me a couple of examples?

26. Is there any information about COVID-19 that you searched for but could not find?

27. Can you talk to me about why you do not use the information from the CDC?

Now, I want you to visit the CDC's website and find the page on "how to wear masks."
(there are a variety of resources on the CDC website for face masks but this is what we would like participants to visit: https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/how-to-wear-cloth-face-coverings.html. You may help or lead participants to find this page; you can put the link in the chat)

28. Please tell me what you think about the face mask information you saw on the CDC's webpage.
    What things did you like the best about it?
    What things did you not like about it?

29. Do you have any trouble:
    Getting to the page, getting around the page, or reading the webpage?
    Tell me about the trouble you had?

30. What other ways could the CDC used to present this information more clearly?

31. Did you understand the words on this webpage?
    Did you understand what the webpage was saying?
    Would you like it if the webpage used words that are easier to understand?

32. Would you come back to the CDC's webpage for more information about COVID-19?
    Please tell me why or why not.

33. What else would you like to tell me about how you have learned about COVID-19?

(if time permits, ask the questions below; if not, skip them)

34. Would you read the COVID-19 information if you could get it printed on paper?
    (wait for the answer; then ask the following probe)
    Can you tell me why?

35. What COVID-19 information would you like to see on a paper?

36. Would you read COVID-19 information if you could get it on a poster?
    (wait for the answer; then ask the following probe)
    Can you tell me why?

37. What COVID-19 information would you like to see on a poster?

Caregiver Group Interview Questions

General Information About the User

1. Can you describe any assistive technology the person you provide care for uses for accessing the internet and computer?

2. Has the person you provide care for ever used the CDC's website or social media platforms, such as YouTube, Facebook, Twitter, or Instagram for COVID-19 related information? (Yes/No question)

3. Has the person you provide care for ever read the CDC's flyers on COVID-19? (Yes/No question)

4. Has the person you provide care for ever seen/read the CDC's posters on COVID-19? (Yes/No question)

*If the majority of the participants **have previously used** the CDC's website or social media platforms for COVID-19 related information, ask questions from 5 to 16.*

*If the majority of the participants **have not used** the CDC's website or social media platforms for COVID-19 related information, ask questions from 17 to 28.*

5. Which CDC platform(s) does the person you provide care for use for finding COVID-19 related information? Website; YouTube; Facebook; Twitter; Instagram; other?

6. How often does the person you provide care to use the CDC platforms for finding COVID-19 related information?

7. What types of COVID-19 related information the person you provide care to search on the CDC's platforms? Can you give me a couple of examples?

8. *(chose one example mentioned the most by the participants)* Did they find what they were looking for in that resource?

9. How would you change that resource to make it more helpful to the person you provide care to?

10. Are there any other COVID-19 related information you would like to see added to the CDC's platforms for the person you provide care to? Which ones?

11. Did the person you provide care to experience accessibility challenges with the CDC's COVID-19 resources?
    (wait for the answers; if even one participant says yes, ask the following probe)
    Can you tell me about those accessibility challenges?

12. Are there alternative accessible formats you would like to see added to the CDC's platforms for the person you provide care to?
    (wait for the answers; if even one participant says yes, ask the following probe)
    Which ones?

13. Would the person you provide care to use Minimized Text Complexity version of the COVID-19 information on the CDC's website if it was made available to them?
    (explain MTC to the group; wait for the answers; then ask the following probes)
    Why?
    Why not?

14. Do you have any other comments about the COVID-19 information on the CDC's platforms or the experiences of the person you provide care to?

(if time permits, ask the questions below; if not, skip them)

15. Would the person you provide care to read the CDC's COVID-19 flyers if they were made accessible to them?
    (wait for the answer, then ask the following probe)
    Why?
    Why not?

16. Would the person you provide care to read the CDC's COVID-19 posters if they were made accessible to them?
    (wait for the answers; then ask the following probes)
    Why?
    Why not?

(thank all the participants and conclude the session)

17. How often does the person you provide care to search for COVID-19 related information?
    (if there is no report from the group for COVID-19 related information, skip to question 21)

18. Where does the person you provide care to get COVID-19 related information?
    (if not getting clear answers, probe: Organization websites? Google search? Social media? Friends and family? Flyers? Posters?)

19. What types of COVID-19 related information does the person you provide care to search? Can you give me a couple of examples?

20. Are there any COVID-19 related information the person you provide care to has searched for but could not find?

21. Can you tell me why the person you provide care to has ever used the CDC's COVID-19 resources?

Now, I want you to visit CDC's website and find the page on "how to wear masks."
(there are a variety of resources on the CDC website for face masks but this is what we would like participants to visit: https://www.cdc.gov/coronavirus/2019-ncov/prevent-getting-sick/how-to-wear-cloth-face-coverings.html. You may help or lead participants to find this page; you can put the link in the chat)

22. Please give me your initial impressions about this resource.
    (tell the group that we are asking them to consider the needs of the persons that are providing care to)

23. Which things did you like about it? Which things did you not like about it? What would you most want to change about it?

24. Would the person you provide care to use a Minimized Text Complexity version of the COVID-19 information on CDC's website, if it was made available to them?
    (wait for the answers; then ask the following probes)
    Why?
    Why not?

25. Are there alternative accessible formats you would like to see added to the CDC's platforms for the person you provide care to?
    (wait for the answers; if even one participant says yes, ask the following probe)
    Which ones?

26. Do you have any other comments about the COVID-19 resources the person you provide care to uses?

(if time permits, ask the questions below; if not, skip them)

27. Would the person you provide care to read the COVID-19 flyers if they were made accessible to them?
    (wait for the answer; then ask the following probes)
    Why?
    Why not?

28. Would the person you provide care to read the CDC's COVID-19 posters if they were made accessible to them?
    (wait for the answer; then ask the following probes)
    Why?
    Why not?

(thank all the participants and conclude the session)

Assistive Technology Outcomes and Benefits
Volume 16 Issue 2, Summer 2022, pp. 45-55
 ISSN 1938-7261
Available online: www.atia.org/atob

Voices from Industry

Access for Deaf and Hard of Hearing Individuals in Informational and Educational Remote Sessions

Sheryl Ballenger, Ph.D., CPACC

Center for Inclusive Design and Innovation
College of Design
Georgia Institute of Technology

Corresponding Author
Sheryl Ballenger, Ph.D.
Center for Inclusive Design and Innovation
College of Design, Georgia Institute of Technology
512 Means Street
Suite 250
Atlanta, GA 30318
Phone: (404) 894-8679
Email: sheryl.ballenger@design.gatech.edu

Author Note

Regarding person-first language: Members of the Deaf community prefer to be referred to by their identity as a Deaf person rather than a person who is deaf. This article uses the phrase "Deaf and hard of hearing individuals."

ABSTRACT

Opportunities to present to remote audiences require access for people with disabilities. The COVID-19 pandemic, with an imperative of social distancing, provided access challenges. Innovative tools, such as artificial intelligence (AI), as used in Automatic Speech Recognition (ASR), became available in many applications. Some community information and higher education programs considered supplying access through ASR text produced by AI software tools. This article's contribution to the field is a comparative

analysis of some ASR software used as speech-to-text accommodations for Deaf and hard of hearing individuals in informational and educational settings. Some nuances of ASR and human Speech-to-Text-Services (STTS) practices are included. The concept of use cases for low-stakes settings and high-stakes settings are introduced. This article also provides a framework for future studies of the efficacy of ASR software used as an accommodation and best practices for using ASR software in informational and educational remote sessions.

Keywords: speech-to-text, artificial intelligence (AI), automatic speech recognition (ASR), auto-generated captions, real-time captioning, accessibility

ACCESS FOR DEAF AND HARD OF HEARING INDIVIDUALS IN INFORMATION AND EDUCATIONAL REMOTE SESSIONS

People who are hard of hearing have a hearing loss ranging from mild to severe. Both volume and clarity are necessary for understanding speech. A person may hear that speech is occurring, but discerning the actual words requires the ability to hear the phonemes of each sound. The term “Deaf” refers to individuals who are culturally Deaf and individuals who experience a profound hearing loss with little or no hearing (World Health Organization, 2020). Members of the Deaf community prefer to be referred to by their identity as a Deaf person rather than a person who is deaf. This article uses the phrase, Deaf and hard of hearing individuals.

Communication access for Deaf and hard of hearing individuals is essential in every aspect of their lives. The Rehabilitation Act of 1973, Section 508, obligates entities sharing informational or educational information remotely to provide access to the audio for Deaf and hard of hearing individuals. When considering remote formats such as webinars, remote meetings or training, public health and safety information, or educational sessions, organizers must be prepared to address the needs of a broad audience with varied abilities (Section508, n.d.). In order to provide access for Deaf and hard of hearing participants, organizers must ensure that audio is visible in remote sessions. Audio must be visible for Deaf and hard of hearing individuals in remote sessions (Alsalamah, 2020).

Before and during the COVID-19 pandemic, the issue of communication disparities for Deaf and hard of hearing individuals was well documented. (Barnett et al., 2011; Hoglind, 2018; National Association for the Deaf, 2021; National Deaf Center on Postsecondary Outcomes, 2020). The novel COVID-19 health information was not accessible to Deaf and hard of hearing individuals. Compounding the existing situation, the usual in-person channels of communication had suddenly disappeared. College classes and school programs moved online, workplaces closed or moved online, and in-person community events and religious services were canceled. Without a contingency plan for continued communication access, the immediate move to online or remote meant no access for Deaf and hard of hearing individuals (Hodges et al., 2020).

In the United States, in March 2020, during the early stages of the COVID-19 pandemic, meetings,

training, college courses, classes, small groups, etc., transitioned to being hosted on remote collaboration tools (Hodges et al., 2020). Faced with the imperative of social distancing, entities providing informational or educational sessions looked to the most expedient audio access option that was available, Automatic Speech Recognition (ASR; Ellcessor, 2020).

A few remote collaboration tools began rolling out ASR as a contrivance. As educators struggled with emergency remote sessions, so did some presenters of community information regarding health guidance. The Center for Inclusive Design and Innovation (CIDI) at Georgia Institute of Technology, a service and research supercenter, informs about best practices in creating accessible environments. When face-to-face interactions shifted to remote during the COVID-19 pandemic, we noticed the abrupt change from human-provided Speech-to-Text-Services (STTS) to either the sudden cancellation of provided access or to the use of ASR-provided access.

Background

The prospect of machines simulating human behaviors has been a dream of humans for hundreds of years (Ekbia & Nardi, 2014). ASR was first related to pattern recognition. The ASR and pattern recognition work are based on computers' power to recognize a pattern in speech and transform it into pertinent information (O'Shaughnessy, 2008). Reporting on the history of ASR, O'Shaughnessy (2008) noted that Bell Labs demonstrated small-vocabulary recognition for digits spoken over the telephone in 1952. Medical reporting and legal dictation implemented ASR in the 1990s, as well as telephone services (Bogdan, 2019; O'Shaughnessy, 2008). Successful ASR started to understand large vocabularies in uncontrolled environments in the 2000s (Bogdan, 2019). YouTube began providing ASR within its platform in 2009 (Alberti & Bacchiani, 2009). Parton's (2016) study showed YouTube's ASR produced 7.7 phrases that were unintelligible or that altered the meaning of the message every minute. Although Parton's (2016) study used videos, the ASR was the best available and is relevant data.

PERSONAL STATEMENT

As an experienced professional working with Deaf and hard of hearing individuals, I am interested in fair and equitable access. One of the many services CIDI provides is real-time human STTS captioning/transcription. CIDI's mission is to improve the human condition, so when new thoughts, technologies, or applications provide equitable access, we welcome and promote these new discoveries when warranted. As CIDI advises our educational customers, grant funders, and research partners, it was helpful to understand the limitations of ASR during the online surge in course delivery and informational sessions during the COVID-19 pandemic. The results have been incorporated into our plans for best practices.

TARGET AUDIENCE AND RELEVANCE

The target audience for this article has increased during the pandemic to include anyone providing remote

delivery of informational and educational sessions. Public health entities, educators and trainers, researchers, private and public companies, and all providers of remote services will benefit from the insight gained from these best practices. I will provide statistical accuracy ratings for leading ASR systems often used as an accommodation for Deaf and hard of hearing individuals. These results establish best practices for using ASR in its current form and when to use human-provided STTS for access to informational and educational content in online delivery systems.

The relevance of this article is to call attention to our responsibility to consider the impact technological advances may have on users. For example, during the 1990s in the United States, there was interest in moving away from braille for blind individuals and moving to the new screen reading software technology. “Braille has remained vital to the literacy of people who are blind, and it continues to thrive despite the predictions of some to the contrary” (Braille Authority of North America, 2011, p.8). The thought of trading braille materials for screen readers neglects some fundamental issues. When blind individuals read braille, they are more aware of word usage and spelling. A person’s understanding is enhanced by reading independently, and the ability to return to reread a section is readily available. Enhanced memory retention is possible when interacting with braille materials. These benefits demonstrate that new technology (i.e., Screen Reading Software) could not completely replace the former technology. Therefore, there is a continued need for braille documents, and there is a need for screen reading technology.

The same can be said for improvements in transcription. Human-provided Speech-to-Text-Services (STTS) are still important, but with improvements in ASR, ASR produced transcripts used in real-time platforms and recorded media are another way to provide immediate access to spoken speech. Through ASR, people using these technologies can experience automatic, no-cost, or low-cost transcripts. However, considerations must be made in determining when ASR use is appropriate to fulfill access needs for Deaf and hard of hearing individuals.

As a side note, there are some hybrid situations where ASR is used for the initial transcription, but a human STTS provider or collaborative editor listens and corrects in real-time (Akita et al., 2015; Wald, 2018; Wald, 2019). In-progress changes to the real-time transcript are distracting and require some re-training for the Deaf and hard of hearing users to delay reading for a few minutes to allow time for the corrected text to appear. In hybrid real-time situations, where most presentations combine visual presentations with speech, this delay in reading the final version puts the Deaf and hard of hearing individual at a disadvantage for understanding. In this case, a Deaf and hard of hearing individual cannot fully participate in discussions or group interactions.

THE CASE FOR AUDIO ACCESS FOR DEAF AND HARD OF HEARING INDIVIDUALS

The National Deaf Center on Postsecondary Outcomes (2019) affirms that it is appropriate to ask a Deaf or hard of hearing individual what their preferred mode of communication is and honor that specific

request. Possible options may include American Sign Language, real-time Speech-to-Text Services (STTS), such as C-Print software, Typewell software, Communication Access Realtime Translation (CART), or Automatic Speech Recognition (ASR). The goal is to provide successful communication, which allows Deaf and hard of hearing individuals to participate fully.

During the COVID-19 pandemic, some Deaf and hard of hearing users of ASR-produced transcripts stated that they found the use of ASR physically draining because ASR required so much concentration to fill in the blanks or make sense of the transcriptions. Recently a colleague using ASR in an educational setting was frustrated over the missed words and incorrect representation of a speech.

However, some Deaf and hard of hearing users of ASR-produced transcripts have found these transcripts helpful. They noticed errors, but the ASR-produced transcripts met their needs in in low-stakes contexts. A low-stakes setting, determined by the Deaf and hard of hearing individual, may offer a use case for ASR-produced transcripts. An example is a small group planning a family celebration. The vital distinction is that low-stakes situations are settings where consequences are either negligible or easily recoverable. Conversely, high-stakes situations may consist of information leading to an exam, training for work-related tasks, health and safety information, job interviews, *et cetera*. In high-stakes situations, consequences have long-term repercussions.

ASR is promoted as a specialized communication service, which is equivalent to humans (National Deaf Center on Postsecondary Outcomes, 2020). Otter AI (2021) mentions that their service is useful for important conversations and personifies their ASR as a helpful assistant. New opportunities throughout the COVID-19 pandemic provided the ability to learn where ASR-produced transcripts may be successful and situations where they may not be successful. I will discuss my professional experiences with some of the nuances in the outcomes between ASR-produced transcripts and human STTS-produced transcripts.

Unnecessary Utterances

A human STTS provider is trained to provide a true representation of the speaker. Occasionally, human STTS providers may omit unnecessary utterances, such as inarticulates; filler words, such as: uh, um, er, ah, like, right, ok, so, and you know, and other unusual speech patterns. In specific settings, omitting inarticulates aids in understanding by the Deaf and hard of hearing user. The ASR software dutifully represents every sound, every “like,” every “um,” every lead-in utterance, and every side comment. The inarticulates, filler words, or unusual speech patterns may be more distracting than meaningful in a textual representation.

The ASR-produced transcript may match precisely word-for-word in some cases, but meaning may be off. For example, the speaker may have a habit of using a lead-in phrase, as in, “Well, actually,” “Apparently,” “Okay, now,” or other possible phrases. The speaker may establish a pattern of using lead-in phrases that a human STTS provider quickly understands do not add meaning. To alleviate confusion, they will omit them. A human STTS provider example sentence, “Well actually, the earth revolves around the sun,” may become “The earth revolves around the sun.” For a human STTS provider, some loss of

precise word-for-word matching is a professional choice to aid in understanding. For some presenters or speakers, precise word-for-word matching may obfuscate a sentence's meaning.

Best Guess

ASR software is designed to capture every utterance. The ASR transcript will display a word for each utterance, whether it is accurate or not. Oneata et al.'s (2021) study supported that ASR systems use "confidence estimates for a number of downstream tasks: propagating uncertainties for automatic speech translation." Confidence estimates are how ASR software makes a "best guess" for words or phrases. These best guesses are not always noticed by Deaf and hard of hearing users in an informational or educational situation. If the "best guess" is plausible, Deaf and hard of hearing users may absorb the wrong information. Conversely, if the "best guess" is noticeably far from the sentence meaning and Deaf and hard of hearing users are skilled in reading English, they may seek guidance to fill in the missing elements and learn to distrust the information.

Human STTS providers intend to remain faithful to the message without replacing a term misunderstood with a "best guess." Therefore, when a human STTS provider does not hear correctly or recognize a spoken term, they are trained to type a parenthetical, such as "[indistinct]" or "[cannot hear]". In this case, Deaf and hard of hearing users are empowered to seek guidance on the missing elements from the speaker or presenter. Humans are highly capable of understanding unknown speakers in poor audio environments, using arbitrary utterances (O'Shaughnessy, 2008).

O'Shaughnessy (2008) states, "ASR functions well in 'matched conditions,' where the system has been previously trained on all: (1) speakers who would test the system, (2) words that may be used, and (3) possible recording conditions" (p. 2977). The perfect conditions for ASR are rare in most real-time human speech cases.

In many situations, human STTS providers are capable of making sense when mishearing. For example, the phrase "I prefer to have a backup plan," in an ASR-produced transcript may read "I prefer to have a back up land." A human STTS provider may have misheard the word backup, but upon hearing the entire phrase and using context, they can provide the meaningful phrase, "I prefer to have a backup plan." The text represents language, and humans are skilled in managing complex human language nuances.

Human STTS providers can summarize without changing the meaning of a statement. As noted, human STTS providers may omit lead-in phrases, such as "Alright," "So now," "Yeah, well," that may be distracting and do not add to the instructional content. Human STTS providers may also move or omit a side comment that interrupts the focus of the presenter's statement. Human STTS providers can display a more digestible sentence for the user.

Comparative Analysis

We conducted a comparative analysis to determine the accuracy of ASR-produced transcripts in adult educational lecture situations. In addition to Ballenger, the researchers included Matthew Blake, IT Manager, and Kenneth Thompson, Application Developer from the CIDI Information Technology team.

Blake and Thompson searched for leading ASR platforms that process audio files. They selected five options (Microsoft Speech to Text, Google Cloud Speech-to-Text, IBM Watson Speech to Text, AWS Transcribe, and Otter.ai) to obtain a sample of ASR software applications for comparison.

We selected several recorded educational lectures from the CIDI repository representative of adult educational content. The selected lectures were presented in English but varied in topic, presenter, and complexity. We limited the number of recorded lectures to five (5), and we reduced the lecture recording lengths to 30 minutes for a total of 150 minutes of audio recordings containing about 16,000 words. In addition, we created a corrected transcript for each recorded audio file to serve as the baseline transcript. We used the baseline transcript to test the accuracy of the ASR-produced transcripts.

The recorded lecture files were named by their topic and then assigned a random numerical suffix from one through five for that topic. Finally, an independent evaluator submitted the five recorded audio files to the five ASR software services. All transcript collection took place during the first quarter of 2020.

We needed a quantitative comparison to determine the accuracy of the ASR-produced transcripts. First, the differences between each ASR transcript and the corresponding baseline transcript were counted to create a quantitative comparison. We used a custom programmatic tool to automate the comparison, allowing automated word-for-word comparisons. The custom programmatic tool counted the number of words that had to be inserted or deleted in an ASR-produced transcript to be identical to the baseline transcript. An accuracy measure was created by dividing the number of correct words in each ASR-produced transcript by the number of total words in the baseline transcript. The accuracy measure shows a percentage of correctness. A higher number means a more accurate transcript. The accuracy measure of each transcription method is shown in Table 1 in ranked order.

Table 1: Accuracy Measure of Each Transcription Method

Rank Order	ASR Software	Accuracy Measure (%)
1	Otter.ai	88
2	Microsoft Speech-to-Text	86
3	AWS Transcribe	78
4	IBM Watson Speech-to-Text	72
5	Google Cloud Speech-to-Text	69

The ASR-produced transcripts were not fully accurate. Inaccurate transcripts would cause Deaf and hard of hearing users to learn inaccurate information. Therefore, ASR-produced transcripts are not equitable access in high-stakes settings for Deaf and hard of hearing individuals. According to the National Deaf Center on Postsecondary Outcomes (2019), “ASR cannot be relied upon due to high rates of inaccuracy” (The National Deaf Center on Postsecondary Outcomes, 2019).

OUTCOMES AND BENEFITS

An outcome during the COVID-19 pandemic that we learned of was that most in-person informational

and educational sessions shifted to remote with little or no thought to providing appropriate accommodations for Deaf and hard of hearing individuals. Likewise, the rushed conversion to ASR-produced transcripts provided during the COVID-19 pandemic was not a quality accommodation for informational and educational settings.

The benefit is that there are some appropriate uses for ASR-produced transcripts. The use is in low-stakes settings. ASR-produced transcripts provide a path to no-cost or low-cost options for this particular use. It is appropriate to ask the Deaf and hard of hearing participants their preference for human STTS-provided captions/transcription or ASR-produced transcription. Understanding that there is a distinct difference in access for high-stakes settings ensures that the Deaf and hard of hearing individual has equitable access for informational and educational communication.

Additionally, this article provides a framework for future studies of the efficacy of ASR software used as an accommodation.

CONCLUSION

At CIDI, we continue to provide human-provided STTS access to remote informational or educational sessions, as ASR software does not provide equitable access for Deaf and hard of hearing individuals. This decision was applied to our involvement with the Centers for Disease Control and Prevention, resulting in accessible human-provided STTS real-time captioning/transcription and American Sign Language for public-facing informational and educational sessions.

For Deaf and hard of hearing participants, ASR-produced transcripts may be helpful for low-stakes information sessions, especially when speaker/presenters have multiple means of representing what they are sharing. The decision of whether to supply human-provided STTS access or ASR-provided access should be determined by the Deaf and hard of hearing user's preference.

As discussed, unnecessary utterances are distracting in a textual representation, and incorrect best guesses change the words and alter the meaning. Perhaps ASR developers could provide a specific ASR application for Deaf and hard of hearing users with the option to omit unnecessary utterances and mark text below a certain confidence level.

Similar to braille for blind individuals, there will remain situations where human STTS-produced transcripts are essential for Deaf and hard of hearing individuals. In audio environments that are less than ideal, human's contextual abilities are much more astute than ASR. For example, some speakers with different speech patterns or accents are better understood by a human STTS provider. High-stakes informational or educational settings where Deaf and hard of hearing individuals will be responsible for understanding and applying the information require human STTS providers. Human STTS providers should be supplied when the reliability of the information is essential.

Determining whether or not in-person or remote informational or educational sessions are accessible, the U.S. Department of Justice (2014) states, “The goal is to ensure that communication with people with these disabilities is equally effective as communication with people without disabilities (p.1). Future studies are necessary to assess how new transcription techniques could benefit Deaf and hard of hearing users and how providing access with ASR could be helpful in certain situations. Remember to seek preferences of audio access from the Deaf and hard of hearing individuals included in your remote environments (The National Deaf Center on Postsecondary Outcomes, 2019).

DECLARATIONS

The findings and conclusions in this report are those of the author(s) and do 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.

REFERENCES

Akita, Y., Kuwahara, N., & Kawahara, T. (2015). Automatic classification of usability of ASR result for real-time captioning of lectures. *Proceedings of APSIPA Annual Summit and Conference* (pp. 19-22). APSIPA. http://sap.ist.i.kyoto-u.ac.jp/EN/bib/intl/AKI-APSIPA15.pdf

Alberti, C., & Bacchiani, M. (2009, December 4). Automatic captioning in YouTube. *Google AI Blog* [Web log post]. https://ai.googleblog.com/2009/12/automatic-captioning-in-youtube.html#:~:text=On%20November%2019%2C%20we%20launched,captions%20for%20videos%20on%20YouTube

Alsalamah, A. (2020). Using captioning services with deaf or hard of hearing students in higher education: a systematic review. *American Annals of the Deaf, 165*(1), 114–127. https://doi.org/10.1353/aad.2020.0012

Barnett, S., McKee, M., Smith, S. R., & Pearson, T. A. (2011). Deaf sign language users, health inequities, and public health: opportunity for social justice. *Preventing Chronic Disease, 8*(2), A45. Retrieved from https://www.cdc.gov/pcd/issues/2011/mar/pdf/10_0065.pdf

Bogdan, I. (2019). Evaluating Google speech-to-text API’s performance for Romanian e-learning resources. *Informatica Economică, 23*(1), 17–25. https://doi.org/10.12948/issn14531305/23.1.2019.02

Braille Authority of North America. (2011). The evolution of braille: can the past help plan the future? (Part 1). http://www.brailleauthority.org/article/evolution_of_braille-part1.pdf

Buchanan, B. (2005). A (very) brief history of artificial intelligence. *AI Magazine, 26*(4), 53. https://doi.org/10.1609/aimag.v26i4.1848

Ekbia, H., & Nardi, B. (2014). Heteromation and its (dis)contents: The invisible division of labor between humans and machines. *First Monday, 19*(6). https://doi.org/10.5210/fm.v19i6.5331

Ellcessor, E. (2020). Three vignettes in pursuit of accessible pandemic teaching. *Communication, Culture and Critique, 14*(2), 324–327. https://doi.org/10.1093/ccc/tcab010

Hodges, C., Moore, S., Lockee, B., Trust, T., & Bond, A. (2020, March 27). The difference between emergency remote teaching and online learning. *Educause Review.* https://er.educause.edu/articles/2020/3/the-difference-between-emergency-remote-teaching-and-online-learning

Hoglind, T. (2018). Healthcare language barriers affect deaf people too. *Boston University School of Public Health.* https://www.bu.edu/sph/news/articles/2018/healthcare-language-barriers-affect-deaf-people-too/

National Association of the Deaf (2021). Position statement on health care access for deaf patients. https://www.nad.org/about-us/position-statements/position-statement-on-health-care-access-for-deaf-patients/

National Deaf Center on Postsecondary Outcomes (2019). *Effective communication tip sheet.* https://www.nationaldeafcenter.org/resource/effective-communication

National Deaf Center on Postsecondary Outcomes (2020, October 27). *Auto captions and Deaf students: Why automatic speech recognition technology is not the answer (yet).* Retrieved April 23, 2021 from https://www.nationaldeafcenter.org/news/auto-captions-and-deaf-students-why-automatic-speech-recognition-technology-not-answer-yet

Oneata, D., Caranica, A., Stan, A., & Cucu, H. (2021). An evaluation of word-level confidence estimation for end-to-end automatic speech recognition. *IEEE Spoken Language Technology Workshop (SLT),* (pp. 258–265). IEEE. https://doi.org/10.1109/SLT48900.2021.9383570

O'Shaughnessy, D. (2008). Automatic speech recognition: history, methods and challenges [Invited paper]. *Pattern Recognition, 41*(10), 2965–2979. https://doi.org/10.1016/j.patcog.2008.05.008

Otter AI. (2021). Otter is where conversations live. Retrieved May 24, 2021 from https://otter.ai/

Parton, B. (2016.). Video captions for online courses: Do YouTube's auto-generated captions meet deaf students' needs? *Journal of Open, Flexible and Distance Learning, 20*(1) 8–18. https://files.eric.ed.gov/fulltext/EJ1112346.pdf

Section508.gov. (n.d.). https://www.section508.gov/create/accessible-meetings/

U.S. Access Board. *Revised 508 standards and 255 guidelines.* Retrieved April 5, 2022 from https://www.access-board.gov/ict

U.S. Department of Justice. (2014). *Effective communication.* www.ada.gov/effective-comm.htm

Wald, M. (2018, June 23 - 25). Using speech recognition transcription to enhance learning from lecture recordings. *International Conference on Education and New Developments* (pp. 111–115). University of Southampton. https://eprints.soton.ac.uk/419608/

Wald, M. (2019, March 17). Enhancing learning through accessible lecture recordings. *Media and Learning*. https://media-and-learning.eu/type/featured-articles/enhancing-learning-through-accessible-lecture-recordings/

World Health Organization. (2020). *Deafness and hearing loss.* https://www.who.int/news-room/fact-sheets/detail/deafness-and-hearing-loss

Assistive Technology Outcomes and Benefits
Volume 16 Issue 2, Summer 2022, pp. 56-73
 ISSN 1938-7261
Available online: www.atia.org/atob

Voices from Industry

Creating Accessible Infographics: Describing Scientific Data in Ways Everyone Can Understand

K. James Monroe, BS and Valerie Morrison, Ph.D.

Center for Inclusive Design and Innovation
College of Design
Georgia Institute of Technology

Corresponding Author
K. James Monroe
Center for Inclusive Design and Innovation
College of Design, Georgia Institute of Technology
512 Means Street
Suite 250
Atlanta, GA 30318
Email: kjamesmonroe@gatech.edu

ABSTRACT

The COVID-19 pandemic has thrust scientific literature into the global spotlight this year, as information about the virus, how to keep safe, and how to get vaccinated has been continually updated at a rapid pace. Much of this information is being conveyed through infographics. This has resulted in an abundance of easy-to-grasp information for sighted people with no learning disabilities, but this positive impact has not been extended to people with visual or learning disabilities. In effect, these infographics often serve to further marginalize individuals with disabilities. Consistent methods for writing descriptions of images should be developed and implemented by first looking at how information moves from working memory to long-term memory, and then examining how cognitive fatigue can inhibit understanding of complex images and scientific information vital to individuals with disabilities. Considering how best to describe scientific images with concise alternative text and in plain language will have clear and immediate benefits for the health and well-being of those with print-related disabilities.

Keywords: infographics, image descriptions, alt text, alternative text, BLV (blind and low vision), dyslexia, ADHD, learning disabilities, cognitive disabilities, cognitive load, image processing, learning from images, scientific diagrams, public health, coronavirus pandemic, COVID-19

CREATING ACCESSIBLE INFOGRAPHICS: DESCRIBING SCIENTIFIC DATA IN WAYS EVERYONE CAN UNDERSTAND

As the COVID-19 pandemic has taken hold in a world dominated by image-focused information sharing, many organizations have released infographics in an attempt to help the public understand the risks and impacts of the virus. This has resulted in an abundance of easy to grasp information for sighted people with no learning disabilities. However, this positive impact has not been extended to people with visual or learning disabilities. These infographics exclude people who cannot see or navigate the infographic, as well as people who need screen-reading capabilities or plain language to understand printed text. Because an infographic with an accessible description can be a source of helpful information for all who come across it, people and organizations wanting to disseminate important information should use infographics along with image descriptions that are designed to be accessible to the greatest number of people. This article will explain how we developed an evidence-based approach to writing image descriptions that are accessible, using studies from the fields of cognitive science and instructional design as well as feedback from screen reader users.

PERSONAL STATEMENTS

K. James Monroe

In my work writing educational alternative text for images in textbooks, I would often get overwhelmed while implementing our quality-control step, because our habit for a long time was to describe every single element of an image in exhaustive detail. We strove to never leave anything out, so that sighted students did not get more information than students who were blind or had low vision; this seemed like the most equitable and appropriate solution. However, if reading it over in the editing process was overwhelming for a sighted person, how much more exhausting would it be for someone without the visual context?

I began to search for studies that gathered feedback from blind and low-vision people about what sort of image descriptions were helpful, but there were almost none out there—only one in 2008 (Gould et al.), and another in 2020 (Stangl et al.). These two studies provided important information, but both were based on a fairly small sample size and yielded only qualitative data. A further limitation is that they were about highly specific sorts of images—the former discussed science, technology, engineering, and math images, while the latter discussed web browsing images, focusing on e-commerce and social media.

Because of this research gap, I decided to approach the problem from a new angle: How do people learn from images? I began with studies that explored the educational value of images, which led to related studies on cognitive load, the concept and study of how much information can actually be absorbed.

Ultimately, if you can understand how learning from images works, and you understand how learning in general works, you can create a description that more accurately duplicates the learning impact of viewing an image. And contrary to what may be assumed, this does not mean including every detail of an image, or necessarily explaining the visual aspects of the image.

Valerie Morrison

In making content accessible for individuals with disabilities, describing images often becomes the most time-consuming part of the process, and it yields the most disagreements about what to include. Managing a team of passionate writers and disability advocates, I've often found myself diplomatically negotiating a conflict about how to approach a particular project, and often it is the STEM projects with complex math equations and scientific diagrams that pose the most challenging questions. Although many companies and programs promise automated image description in the near future, the technology is not there yet, and a human must be part of the equation to translate the visual imagery into words for full understanding. And so we will continue to engage in these vigorous debates, in an effort to arrive at the most accessible solution when it comes to alternative text description.

Working in E-Text, we often encounter the pressures of transforming material quickly into digital formats for students taking courses. We want to be confident that their course materials are accurate and complete so that they can pass their classes and excel on their tests. But over this past year, these pressures have seemed trivial compared to the immense need for precision and speed in remediating material in collaboration with the Centers for Disease Control to educate people about public health and vaccine information during the COVID-19 pandemic. We have learned a great deal from our collaboration, and reexamined our own process of image description, striving for that perfect and elusive balance between comprehensive and effective.

TARGET AUDIENCE AND RELEVANCE

This paper should be of interest to educators of any grade level, accessibility specialists who describe images for educational purposes, media managers for organizations that distribute public health information, and anyone who wishes to share information in an accessible way. We will explain how to write image descriptions in such a way that they provide important information without being too cognitively overwhelming to be useful.

It is a legal requirement to provide alternative text as part of making documents fully accessible, yet there are no legal guidelines describing how to do so. Section 508 of the Rehabilitation Act (1998) does not directly mention image descriptions or even document accessibility; it simply requires "an alternative means of access that allows the individual to use the information and data" to be provided for people with disabilities. Lawsuits on inaccessibility are judged on whether one particular individual was discriminated against by inaccessible services or documents. Thus, rather than following the letter of the law, attention to the spirit of the law is required: We must make sure everyone has access.

Learning from Images

To answer the question "how do people learn from images?" we can turn to studies on instructional design and cognition. In these fields, it is generally accepted that the use of images can create improved learning outcomes (Anglin & Vaez, 2004). The positive impact of including images in an educational text is well-established enough to have been named: the Multimedia Principle (Fletcher & Tobias, 2005). However, these improved learning outcomes are only for specific scenarios; there are elements that must be present, and elements that should not be present, in order for images to be helpful to understanding.

Connection with Cognitive Load

The reason that images are only sometimes helpful is that they have the ability to increase or decrease cognitive load (Anglin & Vaez, 2004; Butcher, 2006; De Koning et al., 2009; Eitel et al., 2013; Folker et al., 2005; Mautone & Mayer, 2001). Cognitive load is the level of thinking effort needed for learning. It is made up of three pieces: the complexity and difficulty inherent to the knowledge (intrinsic load), how many distractors there are (extraneous load), and how much effort it takes for the particular person to process and integrate the information (working memory load). Images can either function as distractors, creating extraneous load, or as an additional mental pathway, decreasing the load on working memory (Carney & Levin, 2002).

Working memory is the amount of short-term memory available to process information. Greer et al. summarized cognitive research on working memory (2013) as allowing for approximately 7 elements at any one time, but only 2 to 4 elements when combining or processing concepts together. The amount of working memory a person has can also be decreased by some learning and cognitive disabilities such as ADHD and reading disabilities (Ghelani et al., 2004).

The Impact of Cognitive Load on Image Processing

For a sighted person without a print-related disability, the combination of words and images allows for the simultaneous use of verbal and visuospatial mental pathways (Artino, 2008), which puts less overall strain on working memory. This works best when the person is able to view the image and then read the verbal information (Eitel et al., 2013). This means that a non-disabled person has to put forth less effort to understand when images are included than when they are not.

However, for a blind or low-vision (BLV) person, it is the opposite: they have to put forth more effort. When a person has to mentally construct the image from a description, or has to parse the image piece by piece and then mentally reassemble it, there is an entire additional mental process that creates increased cognitive load. Since cognitive load of learning from images is inherently greater for BLV learners, we have to reduce strain on working memory as much as possible if we aim to provide equivalent access to information.

People with dyslexia also experience greater cognitive load when processing images than non-disabled people do. An eye-tracking study by Holmqvist Olander et al. showed that people with dyslexia do not spend as much time looking at images, do not look at as many parts of the image, slow down reading text when an image is present, and have decreased scores when images are presented along with text

(2017). This suggests that people with dyslexia experience greater strain on their working memory when images are present, and have more difficulty processing images. However, when measured as images separate from text, children with dyslexia may actually process images more effectively than children who do not have dyslexia (Fan et al., 2014; Hedenius et al., 2013). This may mean that when images are not competing with text, they may be a more efficient way for people with dyslexia to learn. Listening to image descriptions along with text may allow them to have access to the information in a way that is more effective for them to absorb.

Reducing Strain on Working Memory

In order to reduce strain on working memory, we must increase the qualities that ease strain, and decrease the qualities that cause strain. The qualities that ease mental strain are as follows: important information is emphasized, with trends and implications described; content is succinct, with a small number of concepts at a time; and content is well organized. Qualities that cause mental strain include: unnecessary naming tasks, redundancy, describing unimportant aspects, or adding context from outside the image.

Important Information Emphasized, Including Trends and Implications

It is important to cue the listener to important elements because otherwise, “searching for related elements and trying to relate them may impose a high cognitive load” (de Koning et al., 2009). These important elements can include relationships between parts or objects, the purpose of the image in context, and any trends or implications that stand out visually. If images include attention-getting elements like highlighted areas or bolded text, those elements are signals of importance (Mautone & Mayer, 2001) and the objects they point out should be described.

Stangl et al. interviewed 28 people who were blind or had low vision (2020) and noted that the first thing they wanted to know about an image was why it was present: What was the purpose? How was it related to text that was provided with the image? They expressed that the same image would need different descriptions depending on the context. For example, the same image might be described as a group of people standing in a field, or a group of people smiling and waving, or a group of people in long white robes, depending on which aspect is relevant. The purpose of the image is an essential piece of information to be emphasized, and the context must be considered to determine the image’s ultimate purpose.

In addition to the purpose or “why” of the image, trends and implications must be described. de Koning et al. (2009) explain that images are often included in educational materials to make implied relationships more concrete, especially cause and effect. If an arrow is included in an image, the implied meaning of that arrow is what should be described rather than the literal shape. In essence, there should be a focus on the meaning of a symbol, and not its appearance. Demir et al. (2012) describe how bar graphs and line graphs are designed with an intended meaning, and this meaning is predictable enough from the visual aspect alone that a computer can reliably replicate it. That meaning is extracted based on what is easiest to notice in the image. Hegarty (2011) points out that information given in a table is not identical to the same information given in a line graph, because a table requires mental computations for each

data point in order to understand the relationship between them. In contrast, a line graph exists to make the relationship between points easy to grasp; this means that in describing a line graph or other chart, it is the relationships or trends that should be described, rather than the point values. In practice, what this means is that it is necessary to analyze the image for its purpose, its meaning, and its implications before beginning to craft an effective description.

Succinct and Simple Content

An image description should be as succinct and as simple as possible. Gould et al. surveyed 54 BLV people about what they wanted in an image description, and the most common theme was brevity (2008); if it could be shorter, it should be. According to Smith et al., one important way to avoid overloading working memory is to present small amounts of information at a time, or a small number of new concepts at a time (2016). Mayer, Moreno, Boire, and Vagge (1999) examined the process of learning from animations, which mimics a non-sighted user's processing of static images in that a viewer has to hold previous scenes in working memory in order to understand the overall animation, as the viewer cannot see all scenes simultaneously. Mayer et al. point out that a larger amount of information in a single animation will reduce the learner's ability to hold all of the pieces in working memory at the same time, and thus the learner will be less able to integrate the information from the entire animation. Similarly, an image description should be as short as possible and leave out whatever is unnecessary so that a listener can absorb the maximum amount of information.

Organized Content

Organization is essential to a good image description, primarily because it helps provide a scaffold to integrate new information into existing knowledge. Robinson et al. (2003) explain that presenting an overarching view of information before presenting details allows a learner to create a scaffold or schema, which can then hold new pieces of information as they are presented. This can be imagined as a shelf for the working memory, so that rather than having to hold all new information in working memory and sort it out afterward, a learner can sort the new information onto the "shelf" as it is presented. This means it is important to begin with a summary sentence when writing long image descriptions, and to include sub-summaries with especially long image descriptions. Artino also emphasizes the importance of creating schemas, explaining that schemas "effectively augment working memory capacity" (2008), since these "shelves" of information count as one item within working memory.

In addition to organizing information by using summaries and sub-summaries, describing things by their relationship to each other helps to recall the relevant schema, which allows for the use of "shelves." These can be relationships of proximity, priority, structure, causality, sequence, or function. For example, rather than describing a circulatory system by listing the various names of parts, one would describe the flow of blood from the heart through the aorta to arteries, which lead to capillaries where oxygen is removed, which lead to veins, which lead to the lungs to trade carbon dioxide for oxygen, then lead back to the heart. This cue of describing a sequential, structural relationship between parts helps the listener know how to process the material (de Koning et al., 2009; Mayer & Moreno, 2003). In this example, instead of consisting of many separate objects, the circulatory system becomes one object.

Avoid Unnecessary Naming Tasks

Naming, or the recalling of a word associated with a concept, is a unique cognitive process that is impaired in people with dyslexia (Harrison & Stewart, 2019; Howland & Liederman, 2013) and other learning and cognitive disabilities such as ADHD (Rucklidge & Tannock, 2002). Because of this and because naming takes up part of the working memory process (Ghelani et al., 2004), naming tasks should be reduced as much as possible when describing images.

In practice, this means using the same name for an object or person throughout the description, as well as avoiding the use of acronyms or abbreviations unless they have become a word in and of themselves. It also means referring to things descriptively rather than by arbitrary designations—for example, using "the hungry group" and "the fed group" rather than "the left group" and "the right group." For someone who is processing an image mentally, it may be distracting to focus too much on directions or placement; focusing instead on the content or type of group could be more beneficial.

Avoid Redundancy

Redundancy forces a reader or listener to process the same information more than once, which creates extraneous cognitive load, reducing learning outcomes; this is known as the redundancy effect (Mayer & Moreno, 2003). This is especially taxing if the listener has a significant amount of knowledge already, and in studies this "expertise reversal effect" has shown to decrease learning when that is the case (Kalyuga et al., 1999).

In practice, this means integrating text overlays into the description, rather than repeating the text after describing what it labels. It also means not repeating information that is available in the caption or surrounding text. Another way to avoid redundancy is by describing objects or concepts by similarity first and difference second, rather than describing each one separately when there would be a lot of repetition. For example, instead of "a large tree, a medium tree, a small tree, a tall flower, a medium flower, and a short flower," you could instead describe "Three different sizes of tree and flower: tall, medium, and short."

Avoid Describing Unimportant Aspects or Adding Context from Outside the Image

Most images have relevant and irrelevant elements to them, but describing the irrelevant elements will hinder learning by putting additional strain on working memory (Fenesi et al., 2015). Butcher (2006) demonstrates that this includes unimportant details; students had better learning outcomes from a simplified diagram than a detailed diagram. Duesbery et al. found that when the same graph was more decorative, such as a 3-dimensional chart instead of a 2-dimensional chart, participants had a more difficult time understanding them when working memory was under more strain (2011). Unimportant details can be distracting and lead someone to pay attention to the wrong elements of a description (Cromley et al., 2013). People with low working memory capacity, such as people with dyslexia or ADHD, are especially affected by this, as they are less able to block out recalling irrelevant information (Kane & Engle, 2000). Blind and low-vision users affirmed the need for avoiding distracting details, particularly in elaborate diagrams (Gould et al., 2008). What this means in practice is similar to explaining the important elements: Begin with the question "Why is this here?" and then describe the most relevant aspects of the image.

OUTCOMES AND BENEFITS

The Need for Image Description

In this past year, the pandemic has shone a spotlight on scientific literature and the need for accessible graphics, data, and diagrams, as new information about the virus kept changing. Rapid developments in science and technology were being delivered each day on the news, online, and in print publications. In many of these broadcasts and posts, the language was at an extremely high reading level, and accompanying data was inadequately described. Due to the fact that people with disabilities were disproportionately affected by the COVID-19 pandemic, it is imperative that public health information be made accessible with effective description of visual elements. If individuals with disabilities have access to important health mandates and vaccine information, then they can choose to follow the guidance and recommendations and improve health outcomes. What has been proven time and again is that improving the accessibility of graphics and tables benefits all readers, not just those with disabilities.

At CIDI, our accessibility work has broadened our conception of who needs accessible documents. It is not just students who are blind or have low vision who are placing orders for accessible textbooks; increasingly, we see the majority of our orders being placed by sighted individuals. Students who have other print-related disabilities such as dyslexia, dysgraphia, or dyscalculia are using assistive technology to help them process information. Students with ADHD, auditory learners, and students with cognitive impairments also may prefer accessible text to print as it helps them to focus on content, and thus there is an increasing demand for accessible digital formats that satisfy users with many different needs. It is an important clarification to make that when we consider image description and cognitive load for those using assistive technology, it is often being utilized by sighted individuals.

Public health organizations who implement effective image descriptions will be best equipped to raise awareness and successfully spread accurate information. Often, even when well-intentioned people try to focus on making their materials accessible, they make the assumption that visuals will make complex subjects more understandable, and this is not always the case. In matters of public health, all important information should be presented primarily through text, and if visuals are included that also present information, they should be described. If an infographic or diagram contains additional information not represented in the text, it should be accompanied by an image description that encapsulates the information succinctly for both the sighted and non-sighted user equally. Using image descriptions is an egalitarian way to make sure that visual content will be understood by all.

Image description is often considered to be primarily a task that is performed in post-production of a document or website, something that is done to fill in the gaps for individuals who are blind or low-vision only. But with an increasing amount of reading and knowledge-gathering being done online on personal devices such as laptops and phones, often images do not load properly if at all, or content can be spatially distorted due to browser incompatibility or slow loading times. Adding alternative text in the early days of the web allowed users to preview the content of an image before using valuable and limited bandwidth downloading images. The same is true today, in that adding alternative text to images functions as a descriptor for all users, not just those with disabilities. Image description for images that have STEM

content often must function on two levels; it must be the sole method of conveying information for some, plus it must attempt in some way to simplify or interpret the data or information.

How to Approach Image Description

An excellent image description or alternative text description will encapsulate the image and move the listener or reader towards further understanding or comprehension. It is often not effective to just present all the visual information, as this often results in auditory noise or cognitive overload. The most effective image description will provide an overview of the image and then begin to organize that information in helpful ways that will be easy to comprehend and retain. Describing complex images should begin with an overview sentence that summarizes the visual content and provides a framework for the listener. Additional sentences can then be added after this first all-important sentence, to provide additional details or clarification. The importance of that first sentence cannot be stressed enough, as it gives the listener a way in to what is unseen. Starting with details and then eventually landing on the main point will only fatigue the listener, who may already have lost the thread of what was being described. By starting with the most important aspect and moving to detail, that overview sentence at the beginning will capture the listener's attention and establish a scaffolding or outline that can then be filled in with greater detail.

The greatest challenge in describing STEM images is figuring out where to start, and how to encapsulate everything in one sentence. Writing alternative text is more often about editing than writing. We find that it will often take two or three sentences of writing around the main point before you land on the essence of the image, and then deleting those first two sentences to streamline things and reduce cognitive overload for the listener. Editing techniques for revising your image description will improve the accessibility of your visuals, plus raise your own awareness of the art of image description. These editing techniques include:

- Using Clear and Concise Syntax
    - Edit for clarity
    - Simplify word choice
    - Spell out acronyms or symbols
- Organizing Information
    - Organize information in predictable ways
    - Work from general to specific to provide a framework
    - Group like items and describe images by their similarities first, differences second
    - Describe objects or parts in relation to each other: proximity, priority, causality, sequence, or function
    - Describe trends and highlighted or visually emphasized information
- Providing Information in Multiple Modalities
    - Provide information in different or additional ways
    - Add image descriptions as well as short alternative text when possible
    - Transform graphs into tables, and describe trends
    - Present flow charts as lists
- Reducing Redundancies
    - Avoid repeating what is in a caption or the surrounding text

- Edit your description if it becomes wordy
- Integrate symbols or labels into your description: describe the function of symbols, not the appearance of them.

In addition to reading with the above considerations in mind, it helps to have another person review your writing. We often establish a workflow that allows for multiple people to both write and edit alternative text descriptions, so that we catch mistakes and fill in essential details that may have been overlooked. Using tools like spellcheck in Microsoft Word also helps isolate spelling or grammar mistakes, allowing us to optimize how the assistive technology will pronounce each word for maximum clarity. If you don't have the luxury of a large team to assist you with image description, it often helps to use time to your advantage, writing your alternative text and then waiting a full day or more before going back for an editing pass. Once some time has elapsed, you are more likely to have some detachment from your own writing, to pinpoint omissions or confusing syntax. The ultimate goal is to describe things as simply as possible, and often simplicity and elegance in writing takes time and effort.

Collaboration with the Centers for Disease Control

In our work at CIDI providing accessible materials for those with disabilities, we are often fighting the clock, aiming to get textbooks remediated as quickly as possible for students taking a college course so they can keep up with their classmates. We also face the additional pressure of providing quality content, knowing that students may be tested on the material we remediate. Our mission and goal is giving everyone equal access to information, and so our efforts at describing difficult STEM material have always been focused on how to convey information with clarity and precision. The stakes were raised tremendously in our collaborative work with the Centers for Disease Control this past year, in that now we had the responsibility of making sure individuals not only accessed their course information effectively, but understood risks to their physical health. Suddenly, our concerns about whether or not to include details such as gender or ethnicity in our image description seemed theoretical and of little consequence in comparison with information about how and why to make an appointment for a vaccination.

We were truly fortunate in that the CDC cares deeply about accessibility, and their teams were dedicated to getting accessibility right, even if that did take more time and effort than initially planned. The CDC's materials also leaned heavily towards text and easy-to-digest lists of information, and any additional graphics were used either as decoration or reinforcement of the text, which is ideal in terms of accessibility. Illustrations of people following the CDC guidelines that were listed out in text needed scant description, and if they were excluded entirely by the assistive technology, the important content was still contained within the text. Flyers detailing how to quarantine, or how to socially isolate within a home where someone was infected, had simple illustrations echoing the main point of the text instructions. These images played the role of backing up the relevant points of the text and did not present new information that would be inaccessible to some users. When graphics simply illustrate the text, image description becomes far less imperative.

Examples of Infographics and Effective Alternative Text Descriptions

The two flyers featured below were created by the CDC, and are available for download in PDF format.

Similar versions were made with less emphasis on visuals or graphics, that were available for download in accessible Microsoft Word document format, and also for conversion to Braille. These PDF files were both highly accessible to a wide variety of users. All of the text on each flyer could be read aloud by the screen reading software, and all images were fully described by their captions. These two flyers are exemplary in that they use the graphics to reinforce the text content, and thus writing image description becomes incredibly simple; the captions do all of the heavy lifting, and have the added benefit of being available to sighted users as well.

As an exercise, we've written out example image descriptions for each flyer if they were to be shared as images instead of accessible PDF files. If we were to find these flyers shared on social media as a JPG file, we would recommend the following descriptions so that all of the important health content was conveyed adequately. One thing to pay particular attention to is how much of our descriptions focus on the text and not the graphics. This is an ideal way to share information about public health that has visual interest and color, with graphics that do not cause auditory fatigue or involve lengthy description and accessibility work.

Figure 1: Please Read Before Entering

Example alternative text description if this were to be shared as an infographic:

A flyer about coronavirus safety in a shared building. At the top in large text: Please read before entering. There are eleven illustrations of people who should call before coming inside the office: people with fever or chills, a cough, shortness of breath or difficulty breathing, fatigue, muscle or body aches, headache, new loss of taste or smell, sore throat, congestion or runny nose, nausea or vomiting, or diarrhea. The clinic staff may ask you to wear a mask or use tissues to cover your cough. Thank you for helping us to keep our patients and staff safe. Website: cdc.gov/coronavirus

---

Figure 2: Stop the Spread of Germs

Example alternative text description if this were to be shared as an infographic:

A flyer about coronavirus safety titled, Stop the spread of germs: Help prevent the spread of respiratory diseases like COVID-19. Seven tips are illustrated with simple drawings. 1. Stay at least 6 feet (about two arms' length) away from other people. 2. Cover your cough or sneeze with a tissue, then throw the tissue in the trash and wash your hands. 3. When in public, wear a mask over your nose and mouth. 4. Do not touch your eyes, nose, and mouth. 5. Clean and disinfect frequently touched objects and surfaces. 6. Stay home when you are sick, except to get medical care. 7. Wash your hands often with soap and water for at least 20 seconds. Website: cdc.gov/coronavirus

---

Why the Descriptions of Scientific Data Benefits All Users

Graphs of data require a figure caption or descriptive alternative text to be understood by most individuals, not only those with disabilities. The pandemic has turned many of us into researchers this year, as we scour the internet for data on our states, our counties, and the infection rates in areas where our loved ones reside. The websites providing this data often feature complicated graphs showing spikes in infection rates with no text to explain the visual graphs, making these visual elements functionally invisible for those relying on screen-reading technology. These charts are also difficult for the lay person to interpret; a figure caption would help guide people towards an interpretation of the data.

Similarly, table captions that are placed before a table that describes the trends of the data would help all users in understanding the numbers or information contained within that table. Providing information or important content in multiple modalities is a highly effective strategy when looking at STEM content. For instance, writing a detailed figure caption to describe the data trends of a graph, and then reinforcing

that with the visual image, plus adding brief alternative text description to the figure to reinforce that information in different words, means that there are three different modalities of education occurring. The trick would then be to ensure that the figure caption and alt text description are not too redundant or repetitive, so as not to bog down the working memory of the person accessing both modes of information.

Tables are often overlooked in terms of accessibility, as the text can be highlighted and is therefore considered accessible or available to assistive technology. However, those using assistive technology such as JAWS or NVDA know well the difficulty in navigating tables and understanding where you are within the table as the data is read aloud. Any attempt at framing the contents of the table beforehand would be helpful for users knowing how to interpret and perceive the onslaught of data cells being read aloud. A large table with many rows and columns could become a labyrinth for someone using the keyboard to navigate, and writing alternative text for that table to describe the table's structure will give users an overview of the table's layout and overall content. Structural alt text would consist of counting how many rows and columns the table contains, and then listing each column header in order. This simple step allows non-sighted users the ability to hear the contents of the table in one quick overview, and decide whether or not they want to enter into table mode and process all that data. Again, as with figure captions, table captions that precede the table can benefit all users, and guide individuals towards an interpretation of the data.

Especially in the realm of public health, any attempts to encapsulate complicated data and guide individuals towards a greater understanding will have immediate benefits. Making complex material more accessible with effective alt text or captions helps with the understanding and retention of information that could be life-changing or even lifesaving. Providing this extra layer of accessible description and interpretation will also bolster the trust and confidence that the provider has with the public. If data seems too abstruse to decipher, people will lose interest and become frustrated, eventually looking elsewhere for practical information they can understand and apply to their lives. For public health officials looking to make an impact on the disability community, making sure that images are described fully without causing auditory fatigue is of primary importance. Not only will it help with information retention, but it will help retain users, keeping them engaged and coming back for more information, which has been a core feature of this pandemic—the constantly-evolving information and need to keep the public informed, aware, and responsive to new ideas.

In our collaboration with the CDC, the accessible materials that were posted informing people about the pandemic and vaccine were downloaded hundreds of thousands of times, exceeding everyone's expectations, and people came back for more, wanting updates that they could download, print, and share. By crafting documents that included accessible graphics and easy-to-understand text, we were truly making an impact and providing a service that people found useful and instructive. Armed with this important public health information, individuals across all types of disability communities could make informed decisions about their own safety and well-being.

DISCUSSION/CONCLUSIONS

Combining our research on cognitive load and image processing with our practitioner knowledge remediating highly-complex STEM material, we have arrived at the above recommendations for making materials more accessible and easier to comprehend. By providing information in multiple modalities and supplementing alternative text descriptions with captions, complex scientific infographics, graphs, and diagrams can be understood more fully by individuals who may struggle to decipher complex data. Graphics that are used to reinforce the text will help and not hinder understanding, and will function as another modality or pathway to convey information.

Adjacent to the topic of image description, there are many opportunities for further research and studies concerning Plain Language and Minimized Text Complexity. These movements emphasize reducing the complexity of the reading level of text within a document, ensuring that those who read at middle-school or grade-school levels can understand the text fully. Reading levels in various disability communities are often far below national averages, and the need to focus on making the words themselves more accessible should not be overlooked. Karen Erickson and her team at the Center for Literacy and Disability Studies at University of North Carolina, Chapel Hill, have established a robust set of guidelines for reducing the complexity of a text document, and this work goes hand-in-hand with the need to describe images in ways that reduce cognitive load and allow someone to process information effectively.

Our work converting materials for students with print-related disabilities has given us tremendous insight into the wide range of needs when it comes to accessible file formats. Any discussion of accessible graphics should be grounded in practice, and our practice has shown us that some students prefer brief alt text, others want longer comprehensive alt text, and content providers such as publishers or public health officials should aim somewhere in the middle to satisfy the majority of people's needs. Often, the more complex the image, the more detailed the description needs to be, but by following the editing guidelines outlined above, your alt text description should achieve a balance between too little and too much information. In our work, we are always cognizant of the danger of oversimplifying images in our description, and again, it always helps to have another person to edit and fill in missing pieces in your image descriptions whenever possible, especially when that final content could affect someone's health, safety, or lifestyle choices.

DECLARATIONS

The findings and conclusions in this report are those of the author(s) and do 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.

ACKNOWLEDGEMENTS

We would like to acknowledge the years of hard work and practitioner expertise in writing alternative text description in CIDI's E-Text department. Our past and present team members include: Dawn Evans, Tim Georges, Michelle Breaud, Lora-Beth Allen, John Bui, Deanna Mansfield, Nia Lassiter, and Gabriella Cooper. Johan Rempel and Norah Sinclair have also helped us create our guidelines and greatly informed our practice of image description. We also were honored to work with the Centers for Disease Control in a beneficial collaboration that helped us rethink our own alternative text practices, and learn more about disseminating public health information to a wide audience.

REFERENCES

Anglin, G., & Vaez, H. (2004). Visual representations and learning: the role of static and animated graphics. In G.J. Anglin, H. Vaez, & K. L. Cunningham (Eds.), *Handbook of research on educational communications and technology* (2nd ed., pp. 865-916). Routledge. https://doi.org/10.4324/9781410609519

Artino, A. R., Jr. (2008). Cognitive load theory and the role of learner experience: an abbreviated review for educational practitioners. *Association for the Advancement of Computing in Education (AACE) Journal, 16*(4), 425–439. http://www.learntechlib.org/p/25229/

Butcher, K. (2006). Learning from text with diagrams: promoting mental model development and inference generation. *Journal of Educational Psychology, 98*(1), 182–197. https://doi.org/10.1037/0022-0663.98.1.182

Carney, R. N., & Levin, J. R. (2002). Pictorial illustrations still improve students' learning from text. *Educational Psychology Review, 14*(1), 5–26. https://doi.org/10.1023/A:1013176309260

Cromley, J. G., Perez, T. C., Fitzhugh, S. L., Newcombe, N. S., Wills, T. W., & Tanaka, J. C. (2013). Improving students' diagram comprehension with classroom instruction. *Journal of Experimental Education, 81*(4), 511–537. https://doi.org/10.1080/00220973.2012.745465

de Koning, B. B., Tabbers, H. K., Rikers, R. P., & Paas, F. (2009). Towards a framework for attention cueing in instructional animations: guidelines for research and design. *Educational Psychology Review, 21*(2), 113–140. https://doi.org/10.1007/s10648-009-9098-7

Demir, S., Carberry, S., & McCoy, K. F. (2012). Summarizing information graphics textually. *Computational Linguistics, 38*(3), 527–574. https://doi.org/10.1162/COLI_a_00091

Duesbery, L., Werblow, J., & Yovanoff, P. (2011). Graphical literacy moderates the interaction of decorative dimensionality and cognitive demand in computer-based graph comprehension. *Journal of Educational Computing Research, 45*(1)*,* 75–93. https://doi.org/10.2190/EC.45.1.d

Eitel, A., Scheiter, K., Schüler, A., Nyström, M., & Holmqvist, K. (2013). How a picture facilitates the process of learning from text: evidence for scaffolding. *Learning & Instruction, 28,* 48–63. https://doi.org/10.1016/j.learninstruc.2013.05.002

Fan, Q., Anderson, A. W., Davis, N., & Cutting, L. E. (2014). Structural connectivity patterns associated with the putative visual word form area and children's reading ability. *Brain Research, 1586,* 118–129. https://doi.org/10.1016/j.brainres.2014.08.050

Fenesi, B., Sana, F., Kim, J. A., & Shore, D. (2015). Reconceptualizing working memory in educational research. *Educational Psychology Review, 27*(2), 333–351. https://doi.org/10.1007/s10648-014-9286-y

Fletcher, J. D., & Tobias, S. (2005). The multimedia principle. In R. E. Mayer (Ed.), *The Cambridge handbook of multimedia learning* (pp. 117–134). Cambridge University Press. https://doi.org/10.1017/CBO9780511816819.008

Folker, S., Ritter, H., & Sichelschmidt, L. (2005). Processing and integrating multimodal material: the influence of color-coding. *Proceedings of the Annual Conference of the Cognitive Science Society, 27,* 690–695. https://escholarship.org/uc/item/5ch098t2

Ghelani, K., Sidhu, R., Jain, U., & Tannock, R. (2004). Reading comprehension and reading related abilities in adolescents with reading disabilities and attention-deficit/hyperactivity disorder. *Dyslexia, 10*(4), 364–384. https://doi.org/10.1002/dys.285

Gould, B., O'Connell, T., & Freed, G. (2008). *Effective practices for description of science content within digital talking books.* The WGBH National Center for Accessible Media. https://www.wgbh.org/foundation/effective-practices-for-description-of-science-content-within-digital-talking-books

Greer, D. L., Crutchfield, S. A., & Woods, K. L. (2013). Cognitive theory of multimedia learning, instructional design principles, and students with learning disabilities in computer-based and online learning environments. *Journal of Education, 193*(2), 41–51. https://doi.org/10.1177/002205741319300205

Harrison, A. G., & Stewart, M. (2019). Diagnostic implications of the double deficit model for young adolescents with dyslexia. *Dyslexia, 25*(4), 345–359. https://doi.org/10.1002/dys.1638

Hedenius, M., Ullman, M. T., Alm, P. A., Jennische, M., & Persson, J. (2013). Enhanced recognition memory after incidental encoding in children with developmental dyslexia. *PLoS ONE, 8*(5): e63998. https://doi.org/10.1371/journal.pone.0063998

Hegarty, M. (2011). The cognitive science of visual-spatial displays: implications for design. *Topics in Cognitive Science*, *3*(3), 446–474. https://doi.org/10.1111/j.1756-8765.2011.01150.x

Holmqvist Olander, M., Wennås Brante, E., & Nyström, M. (2017). The effect of illustration on improving text comprehension in dyslexic adults. *Dyslexia, 23*(1), 42–65. https://doi.org/10.1002/dys.1545

Howland, K. A., & Liederman, J. (2013). Beyond decoding: Adults with dyslexia have trouble forming unified lexical representations across pseudoword learning episodes. *Journal of Speech, Language, and Hearing Research (JSLHR), 56*(3), 1009–1022. https://doi.org/10.1044/1092-4388(2012/11-0252)

Kalyuga, S., Chandler, P., & Sweller, J. (1999). Managing split-attention and redundancy in multimedia instruction. *Applied Cognitive Psychology, 13*(4), 351–371. https://doi.org/10.1002/(SICI)1099-0720(199908)13:4%3C351::AID-ACP589%3E3.0.CO;2-6

Kane, M. J., & Engle, R. W. (2000). Working-memory capacity, proactive interference, and divided attention: limits on long-term memory retrieval. *Journal of Experimental Psychology: Learning, Memory, and Cognition, 26*(2), 336–358. https://doi.org/10.1037/0278-7393.26.2.336

Mautone, P., & Mayer, R. (2001). Signaling as a cognitive guide in multimedia learning. *Journal of Educational Psychology, 93*(2), 377–389. https://doi.org/10.1037/0022-0663.93.2.377

Mayer, R., Moreno, R., Boire, M., & Vagge, S. (1999). Maximizing constructivist learning from multimedia communications by minimizing cognitive load. *Journal of Educational Psychology, 91*(4), 638–643. https://doi.org/10.1037/0022-0663.91.4.638

Mayer, R. E., & Moreno, R. (2003). Nine ways to reduce cognitive load in multimedia learning. *Educational Psychologist*, *38*(1), 43–52. https://doi.org/10.1207/S15326985EP3801_6

Rehabilitation Act of 1973, Section 508, as amended. 29 U.S.C §794d (1998). https://www.access-board.gov/law/ra.html#section-508-federal-electronic-and-information-technology

Robinson, D. H., Corliss, S. B., Bush, A. M., Bera, S. J., & Tomberlin, T. (2003). Optimal presentation of graphic organizers and text: a case for large bites? *Educational Technology Research and Development, 51*(4), 25–41. https://doi.org/10.1007/BF02504542

Rucklidge, J. J., & Tannock, R. (2002). Neuropsychological profiles of adolescents with ADHD: effects of reading difficulties and gender. *Journal of Child Psychology & Psychiatry*, *43*(8), 988–1003. https://doi.org/10.1111/1469-7610.00227

Smith, J. L. M., Sáez, L., & Doabler, C. T. (2016). Using explicit and systematic instruction to support working memory. *Teaching Exceptional Children,* *48*(6), 275–281. https://doi.org/10.1177/0040059916650633

Stangl, A., Morris, M. R., & Gurari, D. (2020). “Person, shoes, tree. Is the person naked?" What people with vision impairments want in image descriptions [Research article]. *CHI 2020 Conference on Human Factors in Computing Systems* (pp 1–13). Association for Computing Machinery. https://doi.org/10.1145/3313831.3376404

Assistive Technology Outcomes and Benefits
Volume 16 Issue 2, Summer 2022, pp. 74-85
 ISSN 1938-7261
Available online: www.atia.org/atob

Voices from Industry

Inclusive Design Thinking for Health Messaging in American Sign Language during the COVID-19 Pandemic: A Case Study Brief

Norah Sinclair, M.A., Sheryl Ballenger, Ph.D., CPACC, and Maureen Linden, M.S.

Center for Inclusive Design and Innovation
College of Design
Georgia Institute of Technology

Corresponding Author
Norah Sinclair
Center for Inclusive Design and Innovation
College of Design, Georgia Institute of Technology
512 Means Street, Suite 250
Atlanta, GA 30318
Phone: (404) 894-7432
Email: norah.sinclair@design.gatech.edu

ABSTRACT

Health information needs to be accessible to all people, especially in emergencies and critical times of need such as the COVID-19 pandemic. Health information needs to be designed to meet the needs of a broad range of people, including Deaf and hard of hearing people who use American Sign Language.

An Inclusive Design Thinking framework provides the process and structure for collaborative teams to work together to produce solutions that meet the needs of diverse audiences, including people with disabilities. Design Thinking is a human-centered problem-solving method that puts users at the center of the design process. Inclusive Design Thinking includes the end users throughout the design process, considers barriers users may face when accessing information, and seeks to remove these barriers through information design that is accessible to the intended audience.

This case study provides the details of a collaborative effort by Centers for Disease Control and Prevention (CDC), Georgia Tech Center for Inclusive Design and Innovation (CIDI), ASL interpreters, Deaf and hard of hearing community members and advocates, and other community members to design and disseminate health information during the COVID-19 pandemic while addressing health literacy and digital accessibility best practices.

Keywords: American Sign Language, emergency management, risk communications, health education, health literacy, Design Thinking, Inclusive Design, Inclusive Design Thinking

INCLUSIVE DESIGN THINKING FOR HEALTH MESSAGING IN AMERICAN SIGN LANGUAGE DURING THE COVID-19 PANDEMIC: A CASE STUDY BRIEF

In times of a public health emergency, such as COVID-19, public health messaging is of critical importance to the general public and must be communicated in ways that are accessible to the diverse members of the public, including people with disabilities. Centers for Disease Control and Prevention (CDC) needed to communicate health information on COVID-19 pandemic to all members of the community, including Deaf community members who use American Sign Language (ASL). Health information is designed not only to inform but also so that the audience understands why and how to take action. In the case of COVID-19, this meant taking action to protect oneself from contracting COVID-19 and understanding the measures to take if one did contract the virus. To ensure barrier-free access to the written content provided on the CDC website, messaging needed to be in a language that was fully accessible to the Deaf and hard of hearing population (Möbus, 2010). The health information needed to be accurate, accessible, actionable, culturally relevant, and available in the native language of the intended audience.

In partnership with the Center for Inclusive Design and Innovation at Georgia Tech (CIDI), an Inclusive Design Thinking framework was used to develop accessible and understandable COVID-19 materials for users of ASL. An Inclusive Design Thinking framework is a human-centered approach that recognizes that there will always be a diversity of users in an audience and provides a structure for designing and testing materials to meet the needs of diverse users, including people with disabilities. An Inclusive Design Thinking framework includes five phases or stages that provide the map for understanding the needs of the audience, while designing communication materials and testing their effectiveness (Dam & Siang, n. d.).

Inclusive Design Thinking Framework

An Inclusive Design Thinking framework includes the following five phases, although they are not necessarily completed in a linear fashion and may be repeated throughout a project:

- **Empathize and Understand** the audience and the problem or challenge; Identify cultural considerations and needs. Empathy involves codesign. Codesign is a collaborative process that

actively seeks knowledge and ideas from end users (Ku & Lupton, 2020). Empathy, understanding, and codesign occur throughout the process.

- **Define** stakeholders, community members, end users, and team members. In this phase also define best practices and guidelines for developing the health messages and identify which messages will be translated into ASL.
- **Ideate:** Explore and identify possible solutions. The team explored the use of ASL gloss in initial message design.
- **Prototype:** Develop draft messages and record videos in ASL.
- **Test:** Identify community members and user groups to provide feedback and suggestions on the message content and design. Refine and revise messages as needed.

Empathize and Understand Part 1

CDC identified the need to create accessible and culturally relevant messages on COVID-19 guidance for users of ASL. Although CDC had created a number of ASL COVID-19 videos, they wanted to better meet the needs of the ASL community with their message creation and dissemination. CDC conducted stakeholder meetings to gather feedback and recommendations from the Deaf community and subject matter experts, who determined the following:

- Existing videos were at too high of a health literacy level for this population. U.S. Department of Health and Human Services (HHS) has historically defined health literacy as an "individual's capacity to obtain, process, and understand basic health information needed to make appropriate health decisions." (U.S. Department of Health and Human Services, 2010). However more recent definitions developed by the Secretary of Health and Human Services Advisory Panel for Healthy People 2030, places the responsibility on society to provide "accurate health information and services that people can easily find, understand, and use to inform their decisions and actions." Healthy People 2030 now provides both personal health literacy and organizational health literacy definitions:
    - Personal health literacy is the degree to which individuals have the ability to find, understand, and use information and services to inform health-related decisions and actions for themselves and others.
    - Organizational health literacy is the degree to which organizations equitably enable individuals to find, understand, and use information and services to inform health-related decisions and actions for themselves and others (U.S. Department of Health and Human Services, Healthy People 2030).
- It was clear that the ASL interpreter was hearing and the Deaf community preferred the use of Certified Deaf ASL Interpreters.
- The syntax used in the videos leaned toward English syntax, rather than ASL syntax. ASL has its own unique syntax that differs from that of spoken or written English.
- Effective captioning needed to be included with correct timing, responsive text size, and synchronization with the video. Responsive text or font size can be controlled and customized by the end user, for example the color, font, and size of the text can be changed.
- There was the need to indicate or label that the video is in ASL so users could locate the videos.

Define the Problem Statement and the Process for Message Creation

Teams from CDC, the CDC Foundation, the Center for Inclusive Design and Innovation, and a number of members of the accessibility community identified which CDC COVID-19 resources posted on the CDC website received the most views and would be most helpful to the intended audience when translated into the appropriate accessible medium. For the Deaf community, the CDC guidance would be translated into American Sign Language, videotaped, and posted on the CDC's YouTube channel, while videos would also be posted on the Center for Inclusive Design and Innovation's COVID-19 Accessible Materials Website. The materials were also disseminated through online channels such as Twitter and Facebook.

To translate and disseminate CDC guidance on COVID-19 for users of ASL, there was a need to simplify and compress the CDC guidance so that it could more easily be translated into ASL, could be used to create transcripts and closed captions that would be more readable by a Deaf audience, would be better suited for a video format posted on YouTube, and would meet health literacy needs. Culturally Deaf ASL users may learn ASL at a very young age, and English is often acquired as a second language.

Deaf language learners typically experience limited exposure to English print and English phonology, which may contribute to a general lack of access to health information (Villwock et al., 2021). ASL is a fully fledged natural language with formal linguistic structure at all levels (phonological, morphological, and syntactic), and ASL's organization is supported by a similar neural architecture as found in spoken languages (Perniss et al., 2015).

Effective health information must be crafted and presented so that people can easily find, understand, and act on it. CDC (2021) identifies the three As of health literacy. Effective health information should be:

- **accurate:** the information should be both accurate and easy to understand;
- **accessible:** the intended audience needs to be able to find the information and use the information in a format that works for them; and
- **actionable:** the information should be presented in a way that the intended audience can take action on it.

Guided by these health literacy guidelines and others, including the United States Department of Health and Human Services (HHS) National Action Plan to Improve Health Literacy (U.S. Department of Health and Human Services, 2010), HHS Health Literacy Online U.S. Department of Health and Human Services, 2015), the Federal Plain Language Guidelines (PLAIN, 2011), and W3C Writing for Web Accessibility Recommendations (Web Accessibility Initiative W3C. (n.d.), a process was developed to review and revise the CDC COVID-19 guidelines from the text content on the CDC website so that the guidelines could be translated and reformatted as ASL videos accessible to Deaf audiences. The first step was to revise the complex CDC source health guidance from the website into clarified and simplified text phrases suitable for ASL interpreting in short videos while also ensuring that the message was accurate and approved by CDC. In addition to the CDC guidance, it was also important to include important information that may be specific to people with disabilities and culturally relevant information for people who are Deaf or hard of hearing. For example, it was important to include information regarding

face masks with a clear window that would allow a Deaf person to see the lips and facial movements of the person wearing the mask—a family member or teacher for example. Another example included face masks that could be tied behind the head rather than attached to the ears that could be better worn by a person wearing a hearing aid.

The CIDI team, with feedback and approval from the CDC team, used the following process to revise the COVID-19 guidance from the CDC website for ASL translation:

- **Provide one clear main message.** Define what you want the audience to know and be able to do after engaging with your content. If there are several topics, break them into separate documents, webpages, or videos.
- **Put the most important information first.** The audience may not spend much time with the information and may give up if they don't find what they are looking for or see relevant information.
- **Make the content action-oriented.** Tell the audience what to do and how to do it. Write actionable content that focuses on health behavior. Tell users what you want them to do and give them steps to do it.
- **Keep the content focused on one message.** Move related but different content to a new section, document, or video.
- **Use literal, concrete language and words.** Replace abstract words with concrete, specific words. Provide specific examples.
- **Use common easy-to-understand words that are familiar to the audience.** The audience may give up on the content if they are not familiar with or are intimated by its complexity. Define complex terms in context. When using medical terminology, clearly define the word the first time you use it.
- **Keep sentences and paragraphs short and to the point.** Each section of the message should have only one theme or idea. If you introduce a new idea, start a new paragraph and pause between sections in the video.
- **Separate chunks of information to improve readability.** The information needs to look readable. Large blocks of text can look overwhelming. Use of whitespace can help reduce cognitive load. This idea also applies to organizing ASL concepts that are presented in a video.
- **Use a readable font for any text used on the webpage or in the ASL video.** Font size should be least 12 points or 16 pixels. Use common sans serif fonts, like Verdana, Calibri, or Open Sans. Don't use more than 3 fonts on a page.
- **Make headings meaningful, short, and as specific as possible.** Headings should support the content and aid in navigation and support wayfinding. Headings can be used to help introduce different topics in the video.
- **Divide or break instructions into individual steps.** Complex actions can benefit from an If/Then approach, e.g., If you feel very sick, then you need to call the doctor.
- **Provide multiple means or methods of accessing the content.** Some audience members may prefer to watch a video rather than read text. Provide options.
- **Use simple visuals to support written text.** Use images that help people learn. Visuals can help users with limited literacy skills find, understand, communicate, and use health information. Providing different modes of communication can reinforce the message.

As a next step, the CIDI team provided simplified text for ASL translation to a team of certified ASL interpreters to create an ASL gloss version. The ASL gloss version was next approved by the CDC team and used by ASL interpreters when videotaping the message. The ASL interpreter is seen as a competent bilingual who possesses knowledge of the two languages, English and American Sign Language, and knowledge about the ways of speaking in both languages (Roy, 1992). ASL glossing is a written notation system devised to represent ASL (Supalla & Cripps, 2011).

In the field of teaching ASL, glossing is widespread (Supalla et al., 2017). The focus of glossing in ASL is as a bridge to the English meaning (Supalla & Cripps, 2011). Ensuring the ASL meaning matched the English meaning in the CDC guidelines was important. Providing the ASL gloss to the interpreters who were signing the message for videos meant the interpreters were relaying the message as intended in the guidelines. The process of using ASL glossing also provided the means for script approval by the CDC professionals who were not proficient in ASL. The ASL gloss was also implemented in an effort to limit finger spelling in ASL videos to proper nouns and other acronyms. Figure 1 shows an example of text from the revised information with the corresponding ASL gloss.

Figure 1: Revised Text from Script for ASL Translation in Column 1, with the Corresponding ASL Gloss in Column 2

Text from Script to ASL Translation	ASL Gloss
Washing your hands is an important step to protect yourself and others from COVID-19.	COVID-19 SPREAD TO PROTECT SELF, PROTECT OTHER PEOPLE, IMPORTANT DO-DO? WASH-HANDS.
COVID-19 is spread between people who are in close contact with one another, within 6 feet.	COVID-19 SPREAD HOW? HAPPEN PEOPLE 6 FEET CL-2-person-SET-APART, CL-2 Person-MOVE-TOGETHER
COVID-19 spreads when someone who has the virus coughs, sneezes, or talks and spreads it by air droplets.	PERSON SELF INSIDE HAVE FS-VIRUS, COUGH, SNEEZE, TALK SPREAD-AROUND

Empathize and Understand Part 2

The Design Thinking process is not typically a linear process and empathizing and understanding frequently takes place multiple times throughout a project. For a better understanding of user needs, and codesign opportunities, CIDI conducted a needs assessment with members of the Deaf community through remote (online) focus groups with communication facilitation by certified ASL interpreters and hosted on a secure video platform (BlueJeans). During these focus groups, a moderator questioned the participants about what resources they used to find information about COVID-19 and demonstrated the CDC YouTube channel to the participants. Even though there were ASL videos present, participants could not identify them as being ASL interpreted videos as listed in the indexed list of videos. From this needs assessment, recommendations were made to improve the visibility and findability of the ASL videos, including the following:

a. Incorporate the ASL symbol for interpret when presenting links from the website to the YouTube channel, in the #COVID-19 playlist title, as images in the thumbnail for each ASL resource, and in the title of each ASL resource.
b. In ASL video thumbnails, include an image of the ASL interpreter dressed in clothing that contrasts with their skin tone and the video background.
c. Identify ASL video titles in ASL in the video animation GIF.

Providing public health information during the pandemic in the native language of the intended audience whenever possible was of critical importance as is providing ASL interpreters who are community members and trusted resources. During the COVID-19 pandemic, public appearances and broadcast events of state officials with an ASL interpreter on camera was used in many major cities. Health information must reach Deaf and hard of hearing individuals whose primary language is ASL. As an example, in Georgia, during the COVID-19 pandemic, David Cowan, a Deaf interpreter with native ASL, provided ASL interpretation during briefings given by Governor Brian Kemp. During the briefings, Cowan received information from a hearing certified interpreter, who interpreted the briefings given by the Governor and provided the information to Cowan in ASL. According to Cowan, he reads the ASL signs and changes them to the most accessible form for the Deaf. Cowan is viewed as a trusted resource and community member (Stanfield, 2021). Ensuring crucial health information is communicated in the most understood language by trusted resources is important. Involving the Deaf community in the needs assessment and codesign of messages, and using Deaf ASL interpreters, when possible, helped establish trust between the organization and members of the Deaf community.

Ideate and Prototype

The CIDI and CDC collaborative team developed materials incorporating the recommendations from the needs assessment sessions.

Figure 2: Graphic Icon of the ASL Sign for "Interpret"

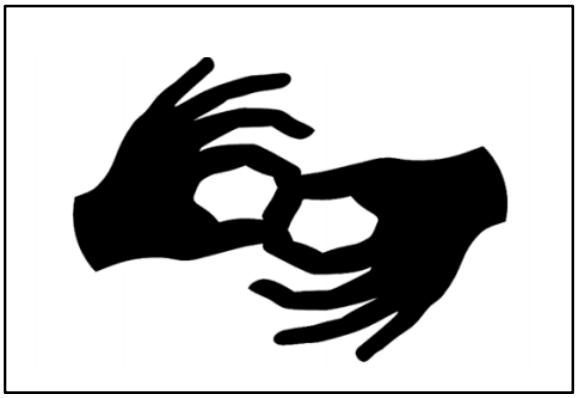
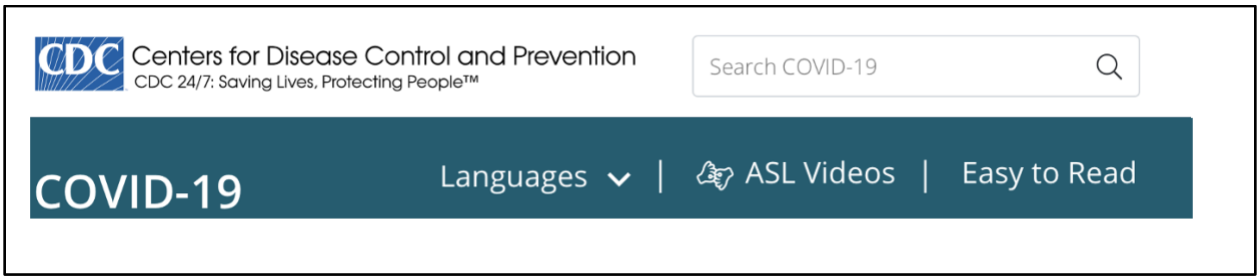


Figure 3: Title Slide of ASL Video with Graphic Icon of the ASL Sign for Interpret, Interpreter Dressed in Contrasting Color, and Video Capture Showing Animated GIF of the Video Title Signed in ASL

Figure 4: Banner Image from CDC COVID-19 Website, Including Graphic Icon of the ASL Sign for Interpret with the Menu Header to Link to "ASL Videos"



To further improve findability and accessibility, the ASL videos were also posted on the CIDI microsite which was developed as an accessible hub for access and dissemination providing COVID-19 resources in alternative formats based upon CDC's guidance, https://cidi.gatech.edu/covid.

The CIDI team, with CDC collaboration and feedback, worked with members of the Georgia Deaf community to produce an ASL video introducing the ASL video series. Several shorter videos were also created to post on social media sites.

Figure 5: Screenshot of ASL Video Series Introduction on cidi.gatech.edu ASL Homepage

Closed captions, an accessibility requirement, were created by the CIDI professional captioning team following best practices from the Described and Captioned Media Program (Described and Captioned Media Program (n.d.), including responsive text size. Responsive text size was an improvement requested in initial stakeholder feedback.

During the COVID-19 pandemic, as many ASL interpreters worked and filmed remotely from home, it was also important to review the ASL videos to ensure that production values including appropriate lighting, background color, and shot framing and composition, were appropriate and consistent. The CIDI team provided this feedback.

Feedback and Testing

Feedback from the Deaf community was positive. Many of the ASL videos were shared widely and reposted on numerous websites that reach a large Deaf community audience. Additional testing with Deaf community members and focus groups will be forthcoming as part of a follow-up project on accessible health and emergency communication.

As the project continued, the need for additional content arose as the COVID-19 pandemic is an ongoing public health emergency. Additional ASL videos on vaccine topics were developed and posted to the CDC YouTube channel and the CIDI Accessible Materials microsite. An additional feature of the ASL vaccine videos was to add the audio content of voiceover narration.

As the pandemic progressed and the Delta variant spread, especially in communities where vaccination rates were low, there was a need to hear from members of the Deaf community who got vaccinated and to hear their reasons for getting vaccinated. An additional ASL Vaccine Testimonial video was produced with ASL users sharing their reasons for getting vaccinated and a call to action asking others to find their reason and to get vaccinated.

In total, over 30 ASL videos were developed. The team recommends this process as useful for other Federal, State and Community groups who need to communicate using American Sign Language during a critical health crisis, emergency situations, and also during the important work of disseminating ongoing health information for the public good, especially in situations in which the agency has little or no knowledge of American Sign Language.

OUTCOMES AND BENEFITS

This article describes the framework of Inclusive Design Thinking as applied to messaging, specifically health messaging in ASL. The Inclusive Design Thinking framework helps teams work together to understand the needs of the intended audience and provides a process for improved team communication and collaboration, which proved to be a successful model when applied to developing messaging in ASL during the COVID-19 pandemic. Although some health messaging in ASL videos was available, they were not being utilized by the Deaf community. Through a needs assessment conducted with members from the Deaf community, we learned that there was a paucity of health guidance in ASL

that could be easily found and understood. Although there were previous videos that included sign language, they were not well identified. Information from the message testing providing guidance for adding visual icons and animated gifs to help users of ASL identify and find the health messaging available in appropriate communication medium of ASL. The message cannot be utilized if it cannot be found. Further, the syntax used in the original videos leaned toward English syntax, rather than ASL syntax. The benefits of applying Inclusive Design Thinking framework allowed for empathizing with and understanding the needs of the intended audience as well as providing the framework that guided collaboration and communication between teams.

This information is foundational in techniques and outcomes to information sharing for a unique population, such as individuals who are Deaf and hard of hearing. These techniques and outcomes may be replicated in other messaging or informational settings that have similar constraints. Through our collaborative efforts, ASL videos of CDC guidance for COVID-19 and COVID-19 vaccinations have currently been viewed more than a million times.

Future efforts to create messaging for individuals who are Deaf and hard of hearing may adopt this foundation of applying Inclusive Design Thinking framework. The framework, as applied, has proven to be successful and served an extremely important task. This could enhance accessibility for Deaf and hard of hearing individuals and create inclusive messaging and information for all future public health messaging, governmental information, or other essential information.

Although the ASL portion of this collaborative project between CIDI and CDC has been completed, the CDC has continued to implement the practices recommended and developed as a result of this collaboration. Strategies and practices from this project also correspond with key recommendations for policy makers regarding Effective Communication from the National Council on Disability 2021 Progress Report: The Impact of COVID-19 on People with Disabilities.

“All federal entities involved in public health, emergency management, and the provision of public announcements or briefings of broad public importance should prepare and disseminate information related to any pandemic or public health emergency in accessible formats, including providing sign language interpretation and/or captions during live and prerecorded video briefings; making all written materials available in alternative formats; and making all online materials accessible (2021 Progress Report: The Impact of COVID-19 on People with Disabilities, 2021). This project provides an Inclusive Design Thinking framework and a case study that other organizations can use as a model to better implement health messaging that is inclusive and accessible to all diverse members of the public including Deaf and hard of hearing people who use ASL as their primary means of communication.

DECLARATIONS

The findings and conclusions in this report are those of the author(s) and do 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.

REFERENCES

Ku, B & Lupton, E. (2020). *Health design thinking: creating products and services for better health*. Cooper Hewitt, Smithsonian Design Museum.

Centers for Disease Control and Prevention (2021, January 12). *Develop & test materials*. https://www.cdc.gov/healthliteracy/developmaterials/index.html

Cokely, D. (1992). *Interpretation: A sociolinguistic model*. Linstok Press.

Dam, R. F., & Siang, T. Y. (n.d.). *What is design thinking and why is it so popular?* https://www.interaction-design.org/literature/article/what-is-design-thinking-and-why-is-it-so-popular

Described and Captioned Media Program (n.d.). https://dcmp.org/learn/598-captioning-key---about-the-key

McKee, M. M., Paasche-Orlow, M. K., Winters, P. C., Fiscella, K., Zazove, P., Sen, A., & Pearson, T. (2015). Assessing health literacy in deaf American Sign Language users. *Journal of Health Communication*, *20*(2), 92–100. https://doi.org/10.1080/10810730.2015.1066468

Möbus, L. (2010). Making web content accessible for the deaf via sign language. *Library Hi Tech*, *28*(4). https://www.emerald.com/insight/publication/issn/0737-8831/vol/28/iss/4

National Council on Disability (2021, October 29). *2021 Progress Report: The impact of COVID-19 on people with disabilities*. https://ncd.gov/progressreport/2021/2021-progress-report#:~:text=KEY%20FINDINGS%3A%20NCD%20found%20that,report's%20seven%20areas%20of%20focus

Perniss, P., Ozyürek, A., & Morgan, G. (2015). The influence of the visual modality on language structure and conventionalization: insights from sign language and gesture. *Topics in Cognitive Science*, *7*(1), 2–11. https://doi.org/10.1111/tops.12127.

Plain Language Action and Information Network (PLAIN) (2011). *Federal plain language guidelines*. https://www.plainlanguage.gov/guidelines/

Roy, C. (1992). A sociolinguistic analysis of the interpreter's role in simultaneous talk in a face-to-face interpreted dialogue. *Sign Language Studies*, *74*, 21–61. http://www.jstor.org/stable/26204611

Stanfield, B. (2021, May 25). *Meet David Cowen, a trusted messenger for Georgians [Video]*. WTVM. https://www.wtvm.com/2021/03/25/meet-david-cowan-trusted-messenger-georgians/

Supalla, S., & Cripps, J. (2011). Toward universal design in reading instruction. *Bilingual Basics*, *12*, 1–13. https://www.tesol.org/

Supalla, S., Cripps, J., & Byrne, A. (2017). Why American Sign Language gloss must matter. *American Annals of the Deaf*, *161*(5), 540–551. https://www.jstor.org/stable/26235305

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion (n.d.). *Healthy People 2030*. https://health.gov/healthypeople/priority-areas/health-literacy-healthy-people-2030

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2010). *National action plan to improve health literacy*. Author.

U.S. Department of Health and Human Services, Office of Disease Prevention and Health Promotion. (2015). *Health Literacy Online: A guide to simplifying the user experience*. https://health.gov/healthliteracyonline/

Villwock, A., Wilkinson, E., Piñar, P., & Morford, J. (2021). Language development in deaf bilinguals: Deaf middle school students co-activate written English and American Sign Language during lexical processing. *Cognition*, *211*, 104642. https://doi.org/10.1016/j.cognition.2021.104642

Web Accessibility Initiative W3C. (n.d.). *Writing for web accessibility*. https://www.w3.org/WAI/tips/writing/#keep-content-clear-and-concise

Assistive Technology Outcomes and Benefits
Volume 16 Issue 2, Summer 2022, pp. 86-103
 ISSN 1938-7261
Available online: www.atia.org/atob

Voices from the Field

Closing the Information Gap: Making COVID-19 Information Accessible for People with Disabilities

Sarah M. Anderson, MPH[1], Alina L. Flores, DrPH, MPH[2], Laura Z. Baldwin, MPH[2], Carolyn P. Phillips, M.Ed.[3], and Jennifer Meunier, MPH[2]

[1]CDC Foundation
[2]Centers for Disease Control and Prevention
[3]Center for Inclusive Design and Innovation
College of Design
Georgia Institute of Technology

Corresponding Author
Sarah M. Anderson, MPH
600 Peachtree Street, NE, Suite 1000
Atlanta, GA 30308
Phone: (404) 653-0790
Email: sanderson@cdcfoundation.org

ABSTRACT

It is essential that people with disabilities have equitable access to COVID-19 communication resources to protect themselves, their families, and their communities. The Accessible Materials and Culturally Relevant Messages for Individuals with Disabilities project aimed to deliver essential COVID-19 information in braille, American Sign Language (ASL), simplified text, and other alternative formats, along with providing additional tools and trainings that people with disabilities and organizations that serve them can use to apply the COVID-19 guidance. Lessons learned from this project can be implemented in future public health emergencies as well as in general public health messaging for people with disabilities. This project, led by Georgia Tech's Center for Inclusive Design and Innovation (CIDI) and with technical assistance from the Centers for Disease Control and Prevention (CDC), was supported by the CDC Foundation, using funds from the CDC Foundation's COVID-19 Emergency Response Fund.

Keywords: COVID-19, accessible communication, American Sign Language, braille, simplified text, disability, public health

INTRODUCTION

The Americans with Disabilities Act (ADA) defines disability as "a physical or mental impairment that substantially limits one or more major life activity" (Americans with Disabilities Act, 1990). Additionally, the Rehabilitation Act of 1973 states that "disability is a natural part of the human experience and in no way diminishes the right of people to live independently; enjoy self-determination; make choices; … and enjoy full inclusion and integration into the economic, political, social, cultural, and educational mainstream of American society". Most people will either have a disability at one time in their lives or know someone who has one, making disability a part of who we all are as humans (CDC, 2018).

An estimated 61 million adults in the United States, or one in four people, report having at least one disability (Okoro et al., 2016). Prevalence differs by disability type, with mobility disabilities being reported as the most prevalent, followed by disabilities in cognition, independent living, hearing, vision, and self-care. Moreover, some adults report having multiple disability types concurrently. Disability types also vary by demographic and other factors. For example, Okoro et al. (2016) found that cognitive disabilities were the most common disability type among younger adults (ages 18–44 years), while mobility disabilities were the most common disability type among middle aged (ages 45–64 years) and older adults (ages ≥65 years). Additionally, a person with four or more disability types concurrently is more likely to live in poverty, have lower educational attainment, and to be seeking employment than an individual with a single disability type (Stevens et al., 2016).

Health information is not often accessible to nor inclusive of people with disabilities. For example, Nguyen et al. (2019) found that people with disabilities reported feeling frustrated while having to search for information, believing that it took a significant amount of effort to find health and medical services information. Identifying and utilizing mediums like telehealth or creating alternate formats can break through these barriers to care for and reach people with disabilities with critical health information, leading to a reduction in access disparities and movement toward achieving health equity. Widespread availability and use of internet-based and other electronic media enables quick and effective relay of health information to a broad audience, including people with disabilities, in a variety of accessible formats. However, gaps in access to the internet still exist, particularly in rural areas, and some people with disabilities experience more challenges with digital health communication due to the information not being in accessible formats (Werner & Shpigelman, 2019). Print media can be an effective tool and such products can be developed for people with basic or below basic literacy; however, print can be a barrier for people with cognitive, literacy, and vision challenges (NIH, 2018). Informational videos, narrated podcasts, and infographics can be used to communicate important health information in creative and visually appealing ways. Finally, informational products in braille and American Sign Language (ASL) can reach people who use these mediums to access critical health information.

The National Assessment of Adult Literacy (NAAL) reports that an estimated 90 million American adults

lack literacy skills to support a "fully productive and secure life" (Berkman et al., 2010). Of those, an estimated 52 million American adults, regardless of disability status, have basic or below basic reading skills (NCES, 2017). Materials created for these individuals only require basic vocabulary knowledge where the reader is not required to understand the structure of sentences or paragraphs (NCES, 2017). Although some people with cognitive disabilities might have lower literacy than adults without cognitive disabilities, as a review by Geukes et al. (2018) indicated, there is minimal information related to health literacy for this population. Between 500,000 and 2 million people who are deaf rely on ASL as their primary form of communication (Mitchell, 2006). According to the 2018 CDC Behavioral Risk Factor Surveillance System, approximately 13 million adults aged 18 years or older reported having a visual disability. Approximately 10% of people who are legally blind use braille (National Federation of the Blind, 2009).

Full civic participation is dependent upon people's ability to understand complex matters that require decision-making and action. These complex matters include health decisions, such as whether to get a vaccination or a health screening. Personal and public well-being depend on effective communication. It is essential that public health and health care communities support health equity by ensuring that timely, accurate, and accessible health information is available for people of all abilities. This is especially important during times of natural disasters, food recalls, pandemics, and vaccine development.

COMMUNICATING WITH PEOPLE WITH DISABILITIES IN THE TIME OF COVID-19

2019 Novel Coronavirus (COVID-19) was first detected in December 2019 and rapidly spread to become a global pandemic (CDC, 2020). Public health agencies at all levels engage in protecting the health of all populations. A critical aspect of this public health response is effective communication, two components of which Reddy & Gupta (2020) note as what information is being conveyed (content) and the communication platforms used to convey it (method). As noted in the World Health Organization's Strategic Communications Framework for Effective Communications (2017), when communicating about urgent health issues, both the content and platforms must be accessible, actionable, credible, relevant, timely, and understandable. Additionally, crisis communication, or communicating during a time of heightened worry, threat, or stress, such as the COVID-19 pandemic, requires "crafting communications that are concise and factual, compassionate, that instill confidence, and that evince organizational competence" (Auer, 2021). As a rapidly evolving health situation requiring multiple, and sometimes changing, messages, including mask wearing, physical distancing, hand hygiene, testing, and vaccination, among others, COVID-19 presents many communication challenges. For some people with disabilities, these challenges can be compounded by difficulties reading, seeing, hearing, and understanding health information that is not communicated in an accessible way.

Federal communications developed for people with disabilities are required to comply with Title II of the ADA and Section 508 of the Rehabilitation Act (USDOJ, 2020). Many requirements under Section 508 can benefit everyone, not exclusively people with disabilities. For example, adding captions to videos is

necessary for people who are deaf or hard of hearing, but may also benefit anyone watching a video while there is background noise. Appropriate color contrast is necessary for people who have low vision but can also benefit everyone, such as when looking at an image on a screen when there is glare from the sun.

Although 508 requirements provide organizations with the guidance, they need to reach a broader audience, they fall short of providing guidance for full accessibility. Even with 508 requirements in place, people with certain disabilities or limitations might not be able to access, understand, or use critical information. For example, while health literacy guidance for web content provides recommendations for enhancing web accessibility, people without accessible technologies or who are blind and do not have access to braille might still be unable to receive important information (HHS, 2021). People with intellectual disabilities, who may not be able to understand guidance due to literacy level, are often also excluded. Finally, an important aspect of communication is that of diversity, representation, and inclusion in images and graphics (Gantman, 2020). In the same way that images represent people of different gender identities, ages, races, and ethnicities, so too should intentional consideration be given to ensuring representation of people with varying disabilities (HHS, 2021).

In March and April 2020, CDC's COVID-19 emergency response team had multiple listening sessions with disability organizations to assess how current health information was perceived and to determine what additional resources were needed. Organizations that serve people with mobility, cognitive, hearing, vision, self-care, and independent living functional disabilities were all included in assessment calls. There was a common desire and request across disability organizations to have COVID-19 content written at lower literacy levels than currently existed and that would be easier to read than the plain language that is required under the Plain Writing Act of 2010 (Plain Writing Act, 2010). There also were specific requests for content in ASL. Aside from accessible communication formats, groups shared ideas on how CDC could better include people with disabilities in scientific guidance as well as educate people with disabilities on how they might apply the guidance to daily life. To address accessible communication gaps during COVID-19, CDC and CDC Foundation partnered with the Center for Inclusive Design and Innovation (CIDI) at Georgia Tech on the Accessible Materials and Culturally Relevant Messages for Individuals with Disabilities project to address the communication needs of people with disabilities during the COVID-19 pandemic as well as disseminate best practices for future public health emergencies.

TARGET AUDIENCE AND RELEVANCE

This article provides information about the Accessible Materials and Culturally Relevant Messages for Individuals with Disabilities project, which created accessible COVID-19 materials for people with disabilities in braille, ASL, and simplified text as well as additional tools and trainings to support the implementation of COVID-19 prevention strategies. The COVID-19 pandemic has underscored the need for public health information that is relevant, understandable, and actionable by all people. People with disabilities are among the groups of people that have been disproportionately impacted by the COVID-19 pandemic (CDC, 2021), so ensuring that critical prevention and mitigation information is accessible and available to this audience in a timely manner is key. Information gathered during the project's needs

assessment, message testing, and implementation phases is not only relevant for the ongoing COVID-19 public health response and in future public health emergencies, but also serves to inform general public health practices to ensure that all people have access to life-saving information.

This article is intended for a number of audiences. Public health professionals engaged in health education, health communication, policy and partnership development, and web development and design, can use the information from this article to ensure that their efforts are culturally relevant, accessible, and inclusive for people with disabilities and their caregivers. This article can also help to support organizations serving people with disabilities, including state and local health departments, to better communicate with their target audiences and facilitate outreach efforts. Lastly, the tools created through this project and the lessons learned can inform future research in health communications and accessible messaging for people with disabilities.

PROJECT OVERVIEW

The *Accessible Materials and Culturally Relevant Messages for Individuals with Disabilities* project, conducted June 22, 2020 to September 30, 2021, aimed to deliver essential COVID-19 information in braille, ASL, simplified text, and other alternative formats to people with disabilities, their families, and caregivers. The project also created additional tools and trainings, including a webinar series, to ensure that COVID-19 information could be applied by people with disabilities. Finally, best practices were shared through publications and trainings detailing how accessible communications can be implemented in future public health emergencies.

This project, led by CIDI, was a CDC Foundation-funded communications initiative to which the CDC was a technical advisor. Product creation and dissemination focused on three primary audiences:

1. people who are blind and use braille
2. people who are deaf or hard of hearing and use ASL
3. people who have intellectual and developmental disabilities who read or listen with understanding below a third-grade reading level and benefit from simplified text.

Two additional audiences were people with mobility limitations and caregivers of people with disabilities who may benefit from the accessible communications materials created through this project.

The project team effectively collaborated with a number of organizations that serve people with disabilities during all phases of development and implementation including the Center for Literacy and Disability Studies, Department of Allied Health Sciences, University of North Carolina at Chapel Hill (UNC), Deaf Link, Inc., and the American Association on Health and Disability (AAHD).

Importantly, the provision of COVID-19 materials in accessible alternate formats meets several principles of Inclusive Design, which aims to remove barriers and enable all people to participate equally. This is achieved by providing a comparable experience by placing people at the heart of the design process, acknowledging diversity and differences, offering choice where a single solution cannot accommodate

everyone, and providing flexibility in the way resources can be accessed (CABE, 2006). The outputs for this project are outlined in Table 1. Each project output is described in more detail below.

Table 1: Project Outputs

Deliverables

Needs Assessment
• Rapid needs assessment with input from organizations serving people with disabilities
• Focus group discussions and in-depth interviews with:
  o People who are blind or who have low vision and use braille
  o People who are Deaf or hard of hearing who use American Sign Language as their primary form of communication
  o People who have intellectual and developmental disabilities who read at a third-grade reading level or below and their caregivers

Web Accessibility Evaluation of Select CDC COVID-19 Webpages
Guidelines for Minimizing the Complexity of Text
Adapting COVID-19 Guidance into Accessible Formats • Braille • American Sign Language • “Easy to Read” • COVID-19 Prevention Videos

Message Testing with Disability Audiences
  o People who are blind or who have low vision and use braille
  o People who are Deaf or hard of hearing who use American Sign Language as their primary form of communication
  o People who have intellectual and developmental disabilities who read at a third-grade reading level or below and their caregivers

Dissemination of Materials and Best Practices • Trainings for CDC staff • Issue briefs • Webinar series • Partner dissemination
Evaluation • Feedback from partners and people with disabilities • Web metrics of accessible COVID-19 materials, tools, and trainings • Number of materials disseminated • Report of lessons learned recommendations for future work

RAPID NEEDS ASSESSMENT

CIDI performed three extensive rapid needs assessments with people with disabilities from throughout the United States. This was a key first step of this project. These informative interview sessions were focused on gathering user insights regarding existing CDC COVID-19 guidance, while also identifying the need for accessible alternative formats for people with disabilities. This feedback and insight were gathered through an approach that included individual interviews, focus groups, and group interviews

with people with disabilities from the project's three primary audiences (Table 1). The three communities that participated in the needs assessment had a wide range of functional abilities, which brought forth the diverse needs for accessible COVID-19 materials. Additional information was gathered from caregivers of people with intellectual and developmental disabilities as well as subject matter experts (SMEs) from more than 40 organizations serving people with disabilities. The needs assessment found that information must be provided in a variety of alternate formats to meet the unique needs of people within these communities.

Web Accessibility Evaluation

The CIDI team conducted web accessibility testing on 32 of CDC's COVID-19 webpages. These pages included the most widely used CDC COVID-19 pages and the most applicable materials used by or for people with disabilities and/or their caregivers as determined by the CIDI team. The web accessibility evaluation documented the types of accessibility issues in accordance with Health and Human Services Accessibility Compliance Checklists (HHS, 2021) and the W3C's international set of guidelines known as Web Content Accessibility Guidelines (WCAG) 2.1 Level AA (2018). Several "best practice" recommendations that fall outside of compliance-level conformance were also part of the evaluation, including feedback from people with disabilities during the needs assessment for the project. The evaluation was presented to CDC and the CDC Foundation in the form of a written report, a brief video showing how various Assistive Technology (AT) would access the pages, and an Excel spreadsheet with additional detail and remediation recommendations. These recommendations were categorized by level of impact and available capacity. Many of the suggested practices that were feasible in the midst of the COVID-19 pandemic were implemented.

ADAPTING CDC'S COVID-19 GUIDANCE INTO ACCESSIBLE FORMATS

Braille and Accessible Digital Files (Word Documents, PDFs, and Digital Braille-ready Files)

The needs assessment conducted for this project highlighted the need for embossed braille materials in addition to accessible digital versions of CDC's COVID-19 guidance. CIDI has a braille production group and is a member of the Braille Authority of North America (BANA). For this work, CIDI also collaborated with SMEs to create and distribute, via mailed packets, verbatim CDC COVID-19 materials for people who are blind or have low vision.

While the braille documents were verbatim CDC guidance, which made adaptation simple, there were numerous concerns that needed to be addressed. Information in the COVID-19 pandemic was frequently evolving. It was important to take steps to ensure that materials embossed and mailed to participants were as "evergreen" as possible, so that they would not soon be out-of-date. When CDC guidance did change, the braille team worked to update Word document versions of the guidance and the Duxbury (braille-ready) digital files so that future embossed copies would be up-to-date. The embossed documents also included a statement that provided the source link for the CDC guidance, the date the

CDC guidance was last updated, the date the guidance was embossed, and instruction that the most current information could be found on CDC's COVID-19 website. This statement was added to promote trust among braille users that they were getting accurate information and allowing them, if possible, to seek current information online.

The braille team created braille versions of 54 of CDC's COVID-19 guidance materials, which were available upon request on the microsite hosted by Georgia Tech (CIDI, 2021). The team also created packets of eight essential COVID-19 resources, as determined through input from the needs assessment and from SMEs. The packets were distributed nationwide through a variety of channels including partnerships with BANA and the Georgia Libraries for Accessible Statewide Services, a network library of the National Library Service for the Blind and Print Disabled. Partners were used for dissemination because they had existing mechanisms for distributing braille to braille users or because they served broad audiences of people who are blind or low vision. All braille was distributed at no cost to the user. As of May 11, 2021, over 46,000 pages of braille were disseminated across the country.

In addition to distributing embossed braille, the CIDI team posted 67 Word documents and CDC PDFs that were remediated for web accessibility to the microsite hosted by Georgia Tech. These materials were available for download for use with AT as well as for people to emboss braille themselves.

American Sign Language

The CIDI team was tasked with writing scripts for ASL videos that would address the concerns about health literacy, cultural relevance, and effective translation into ASL that were raised during the needs assessment and in conversation with partners. The CIDI team simplified several of CDC's COVID-19 guidance pages to a fourth- or fifth-grade reading level. Wording and formatting that would help to facilitate accurate translation into ASL and effective captioning were also used. Two of these resources were initially filmed through a partnership with Deaf Link, Inc. and were message tested with deaf ASL users. Feedback was incorporated into future scripts, and CIDI created a total of 36 ASL scripts that served as the captions and transcripts for 36 ASL videos.

Although CIDI's scope of work initially focused exclusively on English text script development, as CDC filmed and produced the videos, the team provided additional support during ASL video production. The CIDI team wrote several ASL "glossed" scripts, which specify the signs and notations for the facial and body grammar that the interpreter should use. This glossed ASL resource was used on the teleprompter for the interpreter during video filming. Several interpreters chose to create glossed scripts for themselves, and CIDI offered support when requested.

Filming during the COVID-19 pandemic presented unique challenges. Some interpreters and staff were hesitant to film in person. A number of videos were filmed remotely to eliminate risk of COVID-19 spread, but it was difficult to ensure that the videos were of studio quality (adequate lighting, high-resolution cameras, access to a teleprompter, etc.) when they were filmed in the interpreters' home studios. In the end, the majority of the videos were filmed in person, in a studio, but not always at CDC's studio in Atlanta. With support from Deaf Link, Inc. and the Federal Emergency Management Agency (FEMA), a

number of videos were filmed in studios in Texas and Washington, DC. Filming in the studio helped to ensure that the videos were completed efficiently and then could be edited by CDC staff.

In addition, partners shared that Certified Deaf Interpreters (CDIs), who are interpreters who are Deaf themselves, are preferred in the Deaf community compared to hearing interpreters. Although the majority of videos created through this project were filmed using CDIs, it was difficult to always use a CDI as there was a limited number who could film in person or who were able to film remotely with the correct equipment and support.

Based on feedback during the needs assessment and message testing as well as the CIDI team's years of expertise, the team provided a list of recommendations to ensure that the videos were easily accessible for ASL users. This included adding the ASL sign for the word "interpret" () to the video title frame so that it was easily accessible in ASL as well as adding the ASL sign for "interpret" to CDC's COVID-19 website so that it was clear where ASL users could go to obtain content. CIDI reviewed a selection of the videos to provide feedback on signs used and the accuracy of the translation. CIDI also captioned the videos to ensure that the captions matched the signs and followed best-practice recommendations to improve comprehension (e.g., match the words with the signs, slowing the captions down, and including fewer words per line). The ASL videos included animated video titles so that viewers would be able to see the title in ASL and were linked to both the Georgia Tech microsite and the CDC COVID-19 homepage. CIDI also filmed an introductory video for the ASL video series that encouraged people to view the entire playlist.

GUIDELINES FOR MINIMIZING THE COMPLEXITY OF TEXT AND "EASY TO READ" MATERIALS

Efforts to address the communication needs of people who read or listen with understanding below a third-grade reading level, especially people with intellectual and developmental disabilities, were spearheaded by UNC's Center for Literacy and Disability Studies with support from the CIDI team. The first step was to create a set of guidelines for minimizing the complexity of text so that COVID-19 guidance was understandable to this audience. The UNC and CIDI teams began with a scoping review of the literature, which resulted in creation of the Guidelines for Minimizing the Complexity of Text (Center for Literacy and Disability Studies, 2021). These evidence-based guidelines, which were refined throughout the course of this project, provided detailed guidance regarding text (word-level, sentence-level, and document-level); punctuation; layout; and the use of graphics, images, and icons. Examples from the guidelines included ensuring that 92% of the words are among the most frequently occurring words in written English, avoiding use of bullets, avoiding use of graphics unless necessary to support understanding, and avoiding use of negation entirely (Center for Literacy and Disability Studies, 2021).

These guidelines were then applied to 19 of CDC's COVID-19 guidance documents and communications materials, as determined by feedback gathered in the needs assessment and input from CDC SMEs. The materials were simplified using the guidelines to improve readability and to ensure that the overall

reading level was below a third-grade level. Three “Easy to Read” documents were message tested with six people with intellectual and developmental disabilities as well as with their caregivers. Information from the message testing was applied to the simplified text documents and used to further refine the Guidelines for Minimizing the Complexity of Text. Some information gathered from message testing included that additional spacing between lines was needed and that images accompanying the “Easy to Read” materials did not improve understanding. For example, participants described images of people wearing masks or physical distancing as “funny,” especially images without facial features, but could not describe the message that the image was supposed to convey. Given this and additional feedback, images were omitted from the “Easy to Read” materials.

Twenty-four “Easy to Read” materials were created and posted to CDC’s COVID-19 website, with a button to the “Easy to Read” materials on the agency’s COVID-19 homepage. As of March 18, 2022, the “Easy to Read COVID-19 Safety” page on CDC’s website has had nearly 1.3 million views, demonstrating the great demand and need for these materials.

ADDITIONAL TOOLS TO SUPPORT PEOPLE WITH DISABILITIES WHEN APPLYING COVID-19 GUIDANCE

COVID-19 Webinar Series

Information gathered through the needs assessment, message testing, and discussions with internal and external project partners identified a number of gaps in COVID-19 information related to people with disabilities. Numerous partners and people with disabilities asked for additional information on topics such as how to effectively physically distance for people who are blind or have low vision, adaptations for wearing face masks for some people with disabilities, how best to clean durable medical equipment, and how businesses can safely reopen while considering the needs of employees and customers with disabilities.

The CIDI team hosted eight webinars in their COVID-19 Webinar Series to address some of these questions (Table 2). Webinar content was supported by technical assistance from CDC. Presenters included SMEs from CIDI, Tools for Life, Georgia Council on Developmental Disabilities, Southeast ADA Center, and the Center for Leadership in Disability. All webinars were closed-captioned and information was signed by an ASL interpreter. The webinar recording, accessible presentation slides, and session transcript were all posted to the project microsite (CIDI, 2021).

Webinar invitations were sent to the project listserv, shared by project partners, and promoted on social media (Twitter, Facebook, Instagram, and LinkedIn). In total, 8,421 people registered for the webinar series, 3,670 participants attended the live webinar sessions, and 5,350 people have accessed the archived webinar content as of March 22nd, 2022.

Table 2: COVID-19 Webinar Series Presentations

Webinar Title	Date
Apps for Promoting Independence and Safety	November 12, 2020
Sanitizing of Personal Durable Medical Equipment	November 18, 2020
Face Masks and People with Disabilities	December 9, 2020
Mental Health & Resilience within the Disability Community During COVID-19	December 16, 2020
Making Social Media Accessible for People with Disabilities	January 20, 2021
Guidance for Businesses and Employers Considering the Needs of People with Disabilities During COVID-19	February 10, 2021
COVID-19 Vaccines for Caregivers and Personal Care Assistants (PCA)	May 12, 2021
FAQs About COVID-19 Vaccines that People with Disabilities Should Consider	May 26, 2021

COVID-19 Prevention Videos

The CIDI team, in consultation with UNC's Center for Literacy and Disability Studies, also created seven videos about COVID-19. Adults with intellectual and developmental disabilities were the primary audience for these videos, but many other people, with and without disabilities, may benefit. The videos featured people with disabilities and showed peer-to-peer demonstrations of key COVID-19 prevention strategies including wearing a mask, physical distancing, and getting a COVID-19 vaccine using simple language and visuals.

DISSEMINATION

Dissemination of resources was a key focus of this project to ensure that the tools reached the intended population groups. This project quickly built upon existing CDC Foundation, CDC, and CIDI's wide networks of relationships with disability-related organizations at federal, state, regional, and national levels.

The dissemination goal was primarily focused on rapidly getting the accessible COVID-19 guidance to individuals of all ages and disabilities throughout the United States. To accomplish this, CIDI worked with people, some directly and others through partners including AT programs; AT reuse programs; Centers for Independent Living; Area Agencies on Aging; Aging and Disability Resource Centers; University Centers for Excellence in Developmental Disabilities Education, Research, and Service (UCEDD); postsecondary Disability Student Services Providers; secondary schools; libraries; schools for deaf students; a wide range of disability advocacy organizations; and SMEs in the field of disabilities in all states and territories. Dissemination started with CIDI, CDC Foundation, CDC, and AAHD collectively identifying national organizations that serve the intended targeted audiences for the project or identifying individuals who are connected to these organizations by network affiliations. Organizations were invited

to participate in an informational session about the project which highlighted opportunities for collaboration and project promotion. The project team then worked with more than 220 dissemination partners on a national level. Although numerous organizations were sharing information about the project through social media, email, and more, 25 national organizations were actively engaged in dissemination activities as key project partners.

In addition to disseminating the accessible COVID-19 materials, the project aimed to disseminate best practices for communicating with people with disabilities during public health emergencies. CIDI and its partners conducted trainings for CDC staff about the communication needs of people who use ASL, people who use braille, and people who would benefit from "Easy to Read" materials. Issue briefs were developed to support CDC staff when creating accessible materials for people with disabilities and external partners, as well as internal communications.

CHALLENGES, LESSONS LEARNED, AND OPPORTUNITIES

The Value of Partnerships and Engagement with People with Disabilities

As with any project, but especially for projects focused on populations that have been historically marginalized and underrepresented, involving partners throughout the process is crucial as a matter of ethics and culturally informed inclusive practices to create the most effective and well-received initiative possible. This project emphasized the importance of involving people with disabilities and partners who serve people with disabilities at every stage of project development and implementation. Through the needs assessment, important information was gathered from SMEs as well as people with disabilities to inform communications product development. Without the information gathered at this stage, the topics of these materials and the formats created may not have met consumer needs and important considerations for how to ensure that these materials would be accessed by people with disabilities (e.g., adding the ASL sign for "interpret" to videos and web pages) would not have been incorporated. Message testing was also crucial to ensure that materials were accurately translated, culturally relevant, and accessible to people with disabilities. Feedback gathered was incorporated into the products, including increasing the spacing of text and determining not to use images in "Easy to Read" materials as well as adding information about the source and embossing date on braille products. Product dissemination would not have been possible without the efforts of partner organizations sharing information through their channels (e.g., mailing braille through partnerships with the National Library Service, additional organizations that know who needs access to braille materials) and informing the project team of best practices for sharing information (e.g., developing and circulating the ASL introduction video).

A number of new partnerships were established between CDC, CDC Foundation, CIDI, subcontractors (AAHD), UNC's Center for Literacy and Disability Studies, and Deaf Link, Inc., as well as partners enlisted for dissemination (e.g., Georgia Libraries for Accessible Statewide Services). In addition to these specific partnerships, federal, state, and other public health agencies can also take steps to build partnerships now that will support future public health emergencies. Emergency planners can gather input from people with disabilities to be integrated into state and local emergency plans. Key contacts can be established to ensure that there are open lines of communication to support specific needs of people with disabilities

that may evolve throughout a response and to support information dissemination. These relationships can be leveraged in future public health emergencies to gather additional input from people with disabilities as well as share crucial information with communities.

Addressing the Challenge of Rapidly-Evolving Information in an Emergency

Science and guidance from CDC were updated regularly during the COVID-19 pandemic, which posed unique challenges when creating accessible formats. It was important to take steps to ensure that embossed braille and recorded ASL videos, which are expensive to create and difficult if not impossible to edit after release, were not immediately out-of-date.

During material development, CIDI and CDC Foundation staff worked closely with CDC technical advisors to stay up-to-date on new guidance that would impact materials created through this project. Attempts were made to focus on information that would be as "evergreen," or consistent throughout the course of the pandemic, as possible, although there was always a chance that guidance would need to be updated. Each accessible resource would refer consumers back to the CDC source guidance where the most up-to-date information could be found.

Even after initial products were developed and disseminated, updates to braille and "Easy to Read" materials were incorporated when the source guidance changed significantly. Additional measures were taken to make it easier to update ASL videos, if needed. ASL videos were filmed in a "modular format," where sections of the video were divided by chapter headings displayed on the screen. This would make updating the videos easier in the future because a segment of the video could be cut out or re-filmed if needed without having to re-film the entire video.

Overcoming Additional COVID-19-Specific Obstacles

A number of challenges specific to the COVID-19 pandemic had to be overcome to effectively carry out this project. Filming ASL videos in person was difficult because interpreters and production staff were often wary of COVID-19 spread, but filming remotely also posed a number of challenges when it came to video quality. In the end, filming in person with support from partners led to the most efficient and high-quality videos, but at-home filming was possible if interpreters had the proper equipment (e.g., cameras, green screens, and teleprompters) and support. In future public health emergencies, having interpreters film from their homes may be useful to create stand-alone ASL resources or to add ASL to existing videos.

Although not unique to COVID-19, it is often difficult to write scientific information in plain language, and even more so if the information needs to be written below a third-grade reading level. Communication between COVID-19 SMEs and the project teams developing the "Easy to Read" materials was critical to ensure that the science was accurately reflected and the materials followed the Guidelines for Minimizing the Complexity of Text so that they could be understood by the target audience. Additional training and education for health communicators and public health practitioners on how to effectively simplify language can ensure that accessible materials can be developed early in future public health emergencies.

EFFECTIVE DISSEMINATION TO PARTNERS AND PEOPLE WITH DISABILITIES DURING PUBLIC HEALTH EMERGENCIES

This project reached people with disabilities and partners through numerous channels. CDC, the CDC Foundation, CDC, and CIDI shared information with national and local partners through email announcements on various listservs, press releases, articles, social media posts, webinars, and partner phone calls. Sharing the information through links to specific pages on Georgia Tech's microsite as well as CDC's website proved useful. For example, for people using ASL, the weblink to the ASL page would allow them to see the introduction video and animated video titles in one place rather than having to navigate to find each video on CDC's website or YouTube channel. As previously mentioned, partnerships were crucial for effective dissemination. People are more likely to use and apply information that they learn from sources that they trust. Building these relationships helped the project to use dissemination partners that already reached the target audiences.

ENSURING THE COMMUNICATION NEEDS OF PEOPLE WITH DISABILITIES ARE MET IN THE NEXT PUBLIC HEALTH EMERGENCY

This project highlighted several opportunities for education and awareness about people with disabilities and their unique communication needs among health care and public health professionals. Early inclusion of people with disabilities and disability partners is needed during emergency preparedness and response efforts, but many lessons learned from this project can be integrated into everyday public health communications and public health emergency preparedness planning. Using the Guidelines for Minimizing the Complexity of Text to ensure that information is accessible to people with limited literacy skills, creating ASL videos and embossed braille materials, and working to ensure that web materials are as accessible as possible to people using AT will not only ensure that people have access to information now, but can also promote trust with people with disabilities so that they look to public health agencies and organizations as reliable sources of information during an emergency.

This project was an opportunity to not only raise awareness about the importance of accessible health communications and specific considerations for people with disabilities within CDC and CDC Foundation, but also for external partners and audiences. Through the creation and dissemination of these materials, as well as through the trainings conducted as a part of this project, capacity was built that can be used in future public health emergencies at the federal level and can be applied at every level of public health institutions and organizations.

OVERALL OUTCOMES AND BENEFITS

When information is made accessible, everyone benefits. To prevent the spread of COVID-19, information about prevention strategies needs to be accessible for all people to protect themselves and

their communities. The strategies and lessons learned from the Accessible Materials and Culturally Relevant Messages for Individuals with Disabilities project can be applied to future public health emergencies and general practice to ensure that information is accessible and relevant to people with disabilities. Using partnerships established and maintained through this project can also support CDC, CDC Foundation, and other public health agencies and organizations to effectively obtain feedback from and disseminate information to people with disabilities and their caregivers.

DECLARATIONS

The findings and conclusions in this report are those of the author(s) and do 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.

REFERENCES

Americans With Disabilities Act of 1990. Definition of disability. Section 12102. Pub. L. No. 101-336, § 1, 104 Stat. 328 (1990).

Auer, M. R. (2021). Covid-19 crisis communications: The challenge for environmental organizations. *Environmental Science & Policy*, *115*, 151–155. https://doi.org/10.1016/j.envsci.2020.08.009

Benjamin, G., Mitra, M., Graham, C., Krahn, G., Luce, S., Fox, M., Hootman, J., Ghiya, N., and Popovic, T. (2013). CDC grand rounds: public health practices to include persons with disabilities. *Morbidity and Mortality Weekly Report (MMWR)*, *62*(34), 697-701. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6234a3.htm?s_cid=mm6234a3_w

Berkman, N., Davis, TC., McCormack, L. (2010). Health literacy: What is it? *Journal of Health Communication*, *15*(S2), 9-19, https://doi.org/10.1080/10810730.2010.499985

Centers for Disease Control and Prevention (2020). *About COVID-19*. https://www.cdc.gov/coronavirus/2019-ncov/cdcresponse/about-COVID-19.html

Centers for Disease Control and Prevention (2012). Current cigarette smoking among adults—United States, 2011. *Morbidity and Mortality Weekly Report (MMWR)*, *61*(44); 889-894. https://www.cdc.gov/mmwr/preview/mmwrhtml/mm6144a2.htm#:~:text=In%202011%2C%20an%20estimated%2019.0,9.7%20million)%20smoked%20some%20days.

Centers for Disease Control and Prevention (2018). *CDC: 1 in 4 US adults live with a disability [Press release]*. https://www.cdc.gov/media/releases/2018/p0816-disability.html

Centers for Disease Control and Prevention (2021). *People with disabilities*. https://www.cdc.gov/coronavirus/2019-ncov/need-extra-precautions/people-with-disabilities.html

Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability (2021). *Disability and health data system (DHDS) data [online*]. Retrieved April 25, 2021 from https://dhds.cdc.gov

Center for Inclusive Design and Innovation (CIDI) at Georgia Tech (2021). *COVID-19 accessible resources*. Retrieved April 25, 2021 from https://cidi.gatech.edu/covid

Center for Literacy & Disability Studies, Department of Allied Health Sciences, University of North Carolina at Chapel Hill (2021). *Guidelines for minimizing the complexity of text*. https://cidi.gatech.edu/sites/default/files/2021-02/Minimized%20Text%20Complexity%20Guidelines%20%5Bversion%202.03.2021%5D.pdf

Commission for Architecture and the Built Environment (CABE) (2006). *The principles of inclusive design. (They include you)*. https://www.designcouncil.org.uk/sites/default/files/asset/document/the-principles-of-inclusive-design.pdf

Courtney-Long, E., Stevens, A., Caraballo, R., Ramon, I., & Armour, B. S. (2014). Disparities in current cigarette smoking prevalence by type of disability, 2009–2011. *Public Health Reports*, *129*(3), 252–60. https://doi.org/10.1177/003335491412900307

Cree, R. A., Okoro, C. A., Zack, M. M., & Carbone, E. (2020). Frequent mental distress among adults, by disability status, disability type, and selected characteristics — United States, 2018. *Morbidity and Mortality Weekly Report (MMWR)*, *69*(36), 1238–1243. http://dx.doi.org/10.15585/mmwr.mm6936a2

Drainoni, M., Lee-Hood, E., Tobias, C., Bachman, S., Andrew, J., & Maisels, L. (2006). Cross-disability experiences of barriers to health-care access: Consumer perspectives. *Journal of Disability Policy Studies*, *17*(2), 101–115. http://dx.doi.org/10.1177/10442073060170020101

Gantman, M. M. (2020). *A guide to diversity, equity, and inclusion in communications*. Forbes. https://www.forbes.com/sites/forbescommunicationscouncil/2020/10/21/a-guide-to-diversity-equity-and-inclusion-in-communications/?sh=6fe0edc22b54

Geukes, C., Bruland, D., & Latteck, Ä. -D. (2018). Health literacy in people with intellectual disabilities: A mixed-method literature review. *Kontakt*, *20*(4), e416–e423. http://dx.doi.org/10.1016/j.kontakt.2018.10.008

Health and Human Services (HHS) (2021). *Accessibility and compliance checklists*. Retrieved April 28, 2021 from https://www.hhs.gov/web/section-508/accessibility-checklists/index.html

Kaiser Family Foundation (2003). *Understanding the health-care needs and experiences of people with disabilities: Findings from a 2003 survey*. Retrieved from http://www.kff.org/medicare/6106.cfm

Kinne, S., Patrick, D. L., & Doyle, D. L. (2004). Prevalence of secondary conditions among people with disabilities. *American Journal of Public Health*, *94*(3), 443–445. https://doi.org/10.2105/ajph.94.3.443

Mitchell, R. E. (2006). How many deaf people are there in the United States? Estimates from the survey of income and program participation. *The Journal of Deaf Studies and Deaf Education*, *11*(1), 112–119. http://dx.doi.org/10.1093/deafed/enj004

National Center for Education Statistics (NCES) (2017). *PIAAC proficiency levels for literacy*. https://nces.ed.gov/surveys/piaac/litproficiencylevel.asp

National Federation for the Blind (2009). *The Braille literacy crisis in America*. https://www.nfb.org/images/nfb/documents/pdf/braille_literacy_report_web.pdf

National Institutes of Health (NIH) (2018). *Clear communication: clear & simple*. https://www.nih.gov/institutes-nih/nih-office-director/office-communications-public-liaison/clear-communication/clear-simple

Nguyen, J., & Gilbert, L. (2019). Health literacy among individuals with disabilities: a health information national trends survey analysis. *The Permanente Journal*, *23*, 19.034. http://dx.doi.org/10.7812/TPP/19.034

Okoro, C. A., Hollis, N. D., Cyrus, A. C., & Griffin-Blake, S. (2016). Prevalence of disabilities and health care access by disability status and type among adults—United States, 2016. *Morbidity and Mortality Weekly Report (MMWR)*, *67*(32), 882–887. https://www.cdc.gov/mmwr/volumes/67/wr/mm6732a3.htm

Plain Writing Act of 2010. Pub. L. 111–274. 124 Stat. 2861 (2010).

Reddy, B. V., & Gupta, A. (2020). Importance of effective communication during COVID-19 infodemic. *Journal of Family Medicine and Primary Care*, *9*(8), 3793-3796. http://dx.doi.org/10.4103/jfmpc.jfmpc_719_20

Rehabilitation Act of 1973. Section 2. Pub. L. No 93-112, 87 Stat 355 (1973). As amended through P. L. 114-95 (2015).

Slabaugh, S. L., Shah, M., Zack, M., Happe, L., Cordier, T., Havens, E., Davidson, E., Miao, M., Prewitt, T., & Jia, H. (2017). Leveraging health-related quality of life in population health management: the case for healthy days. *Population Health Management*, *20*(1), 13–22. http://dx.doi.org/10.1089/pop.2015.0162

Stevens, A. C., Carroll, D. D., Courtney-Long, E. A., Zhang, Q. C., Sloan, M. L., Griffin-Blake, S., & Peacock, G. (2016). Adults with one or more functional disabilities—United States, 2011–2014. *Morbidity and Mortality Weekly Report (MMWR)*, *65*(38), 1021-1025. http://dx.doi.org/10.15585/mmwr.mm6538a1

U.S. Department of Justice (USDOJ) (2020). *ADA best practices tool kit for state and local governments: Chapter 3, General effective communication requirements under Title II of the ADA*. Retrieved from https://www.ada.gov/pcatoolkit/chap3toolkit.htm.

U.S. Department of Health and Human Services (HHS), Office of Disease Prevention and Health Promotion (2015). *Health literacy online: A guide to simplifying the user experience*. https://health.gov/healthliteracyonline/

W3C World Wide Web Consortium (2018). *Web content accessibility guidelines (WCAG) 2.1*. Retrieved April 29, 2021 from: https://www.w3.org/TR/WCAG21/.

Werner, S., & Shpigelman, C. N. (2019). Information and communication technologies: where are persons with intellectual disabilities? *Israel Journal of Health Policy Research*, *8*(1), 6. http://dx.doi.org/10.1186/s13584-018-0282-4

World Health Organization (2017). *WHO strategic communications framework for effective communications*. https://cdn.who.int/media/docs/default-source/documents/communication-framework.pdf?sfvrsn=93aa6138_0

Assistive Technology Outcomes and Benefits
Volume 16 Issue 2, Summer 2022, pp. 104-110
 ISSN 1938-7261
Available online: www.atia.org/atob

Voices from the Field

"Include Me": Implementing Inclusive and Accessible Communication in Public Health

Alina L. Flores, DrPH, MPH, Jennifer Meunier, MPH, and Georgina Peacock, MD, MPH

Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities:
Division of Human Development and Disabilities

Corresponding Author
Alina L. Flores
Centers for Disease Control and Prevention
National Center on Birth Defects and Developmental Disabilities
Division of Human Development and Disabilities
4770 Buford Highway
MS S106-4
Atlanta, GA 30341
Email: ail5@cdc.gov

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": IMPLEMENTING INCLUSIVE AND ACCESSIBLE COMMUNICATION IN PUBLIC HEALTH

"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 to experience a wide variety of health problems (Gleason et al., 2021; Tarasoff, 2020; van Schrojenstein Lantman-de Valk, 2000), experience challenges to accessing quality health care (Evenhuis, 2001; Sakellariou, 2017), have increased morbidity (Kamalakannan, 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.

REFERENCES

Evenhuis, H. M., Henderson, C. M., Beange, H., Lennox, N., & Chicoine, B. (2001). Healthy ageing – adults with intellectual disabilities. Physical health issues. *Journal of Applied Research in Intellectual Disabilities, 14*(3), 175–194. https://doi.org/10.1046/j.1468-3148.2001.00068.x

Federal Communications Commission (FCC) (2020). *Section 508 of the Rehabilitation Act.* https://www.fcc.gov/general/section-508-rehabilitation-act.

Gleason, J., Ross, W., Fossi, A., Blonsky, H., Tobias, J., & Stephens, M. (2021). The devastating impact of COVID-19 on individuals with intellectual disabilities in the United States. *NEJM Catalyst,* 1–12. https://catalyst.nejm.org/doi/full/10.1056/CAT.21.005

Kamalakannan, S., Bhattacharjya, S., Bogdanova, Y., Papadimitriou, C., Arango-Lasprilla, J.C., Bentley, J., Jesus, T.S. (2021). Health risks and consequences of a COVID-19 infection for people with disabilities: scoping review and descriptive thematic analysis. *International Journal of Environmental Research in Public Health, 18*(8), 4348. https://doi.org/10.3390/ijerph18084348

Koyama, A. K., Koumans, E. H., Sircar, K., Lavery, A., Hsu, J., Ryerson, A. B., & Siegel, D. A. (2022). Severe outcomes, readmission, and length of stay among COVID-19 patients with intellectual and developmental disabilities. *International Journal of Infectious Diseases, 116,* 328–330. https://doi.org/10.1016/j.ijid.2022.01.038

Morgan, C. L., Sheepers, M. I. A., & Kerr, M. P. (2001). Mortality in patients with intellectual disability and epilepsy. *Current Opinion in Psychiatry, 14*(5), 471–475. https://doi.org/10.1097/00001504-200109000-00008

Reichard, A., Haile, E., & Morris, A. (2019). Characteristics of Medicare beneficiaries with intellectual or developmental disabilities. *Intellectual and Developmental Disabilities, 57*(5), 405–420. https://doi.org/10.1352/1934-9556-57.5.405

Sakellariou, D., & Rotarou, E. S. (2017). Access to healthcare for men and women with disabilities in the UK: secondary analysis of cross-sectional data. *BMJ Open, 7*(8), e016614. https://doi.org/10.1136/bmjopen-2017-016614

Schalock, R. L., Borthwick-Duffy, S. A., Bradley, V. J., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., Gomez, S. C., Lachapelle, Y., Luckasson, R., Reeve, A., Shogren, K. A., Snell, M. E., Spreat. S., Tassé, M. J., Thompson, J. R., Verdugo-Alonso, M., Wehmeyer, M. L., & Yaeger, M. H. (2010). *Intellectual Disability: Definition, classification, and systems of supports* (11th ed.). American Association on Intellectual and Developmental Disabilities.

Tarasoff, L. A., Ravindran, S., Malik, H., Salaeva, D., & Brown, H. K. (2020). Maternal disability and risk for pregnancy, delivery, and postpartum complications: a systematic review and meta-analysis. *American Journal of Obstetrics and Gynecology, 222*(1), e1-27, e32. https://doi.org/10.1016/j.ajog.2019.07.015

Traci, M. A., Seekins, T., Szalda-Petree, A., & Ravesloot, C. (2002). Assessing secondary conditions among adults with developmental disabilities: A preliminary study. *Mental Retardation, 40*(2), 119–131. https://doi.org/10.1352/0047-6765(2002)040<0119:ASCAAW>2.0.CO;2

U.S. Department of Health and Human Services (USDHHS). (2005). *The surgeon general's call to action to improve the health and wellness of persons with disabilities.* US Department of Health and Human Services, Office of the Surgeon General.

U.S. Department of Health and Human Services (USDHHS), Office of Disease Prevention and Health Promotion. (2016). *Health literacy online: a guide to simplifying the user experience.* Retrieved January 10, 2020 from https://health.gov/healthliteracyonline/

U.S. Department of Justice (USDOJ). (2007). *ADA best practices tool kit for state and local governments: chapter 3, general effective communication requirements under Title II of the ADA.* Retrieved February 2, 2020 from https://www.ada.gov/pcatoolkit/chap3toolkit.htm.

U.S. Government Printing Office (USGPO). (2010). *Public Law 111–274 — Oct. 13, 2010, 124 Stat. 2861. House Reports: No. 111-432 (Comm. on Oversight and Government Reform). Congressional record, 156. 2010*. Retrieved January 10, 2020 from https://www.govinfo.gov/content/pkg/PLAW-111publ274/pdf/PLAW-111publ274.pdf.

van Schrojenstein Lantman-de Valk, H. (2005). Health in people with intellectual disabilities: current knowledge and gaps in knowledge. *Journal of Applied Research in Intellectual Disabilities, 18*(4), 325–333. https://doi.org/10.1111/j.1468-3148.2005.0026

van Schrojenstein Lantman-de Valk, H. M. J., Metsemakers, J. F. M., Haveman, M. J., & Crebolder, H. F. J. M. (2000). Health problems in people with intellectual disability in general practice: A comparative study. *Family Practice, 17*(5), 405–407. https://doi.org/10.1093/fampra/17.5.405

Assistive Technology Outcomes and Benefits
Volume 16 Issue 2, Summer 2022, pp. 111-126
 ISSN 1938-7261
Available online: www.atia.org/atob

Voices from the Field
Building an Effective Model to Disseminate Accessible COVID-19 Guidance

Elizabeth Persaud, BA, Carolyn P. Phillips, M.Ed., and Patricia Redmon, MBA

Center for Inclusive Design and Innovation
College of Design
Georgia Institute of Technology

Corresponding Author
Elizabeth A. Persaud
Center for Inclusive Design and Innovation
College of Design, Georgia Institute of Technology
512 Means Street, Suite 250
Atlanta, GA 30318
Phone: (404) 385-6573
Email: liz.persaud@gatfl.gatech.edu

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.

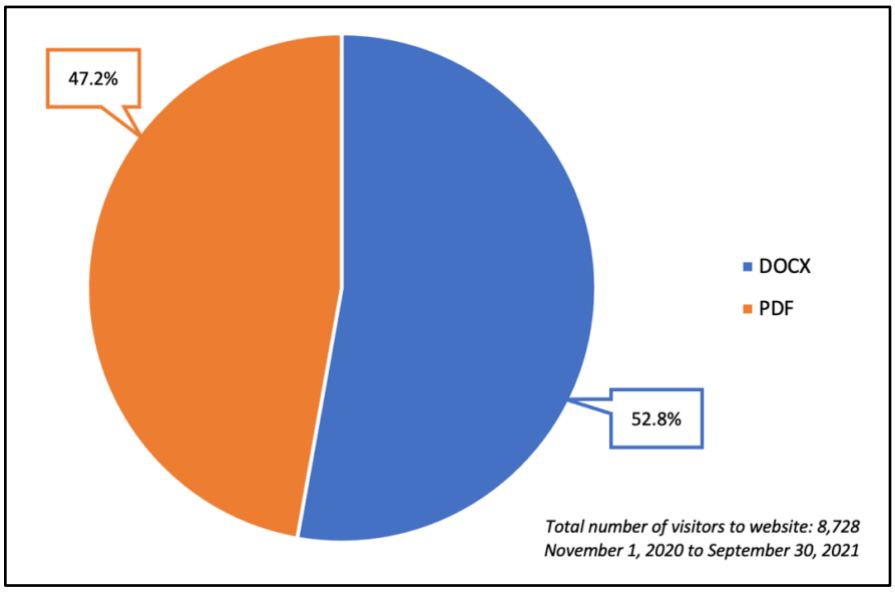
Simplified Text Products for Ease of Reading

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

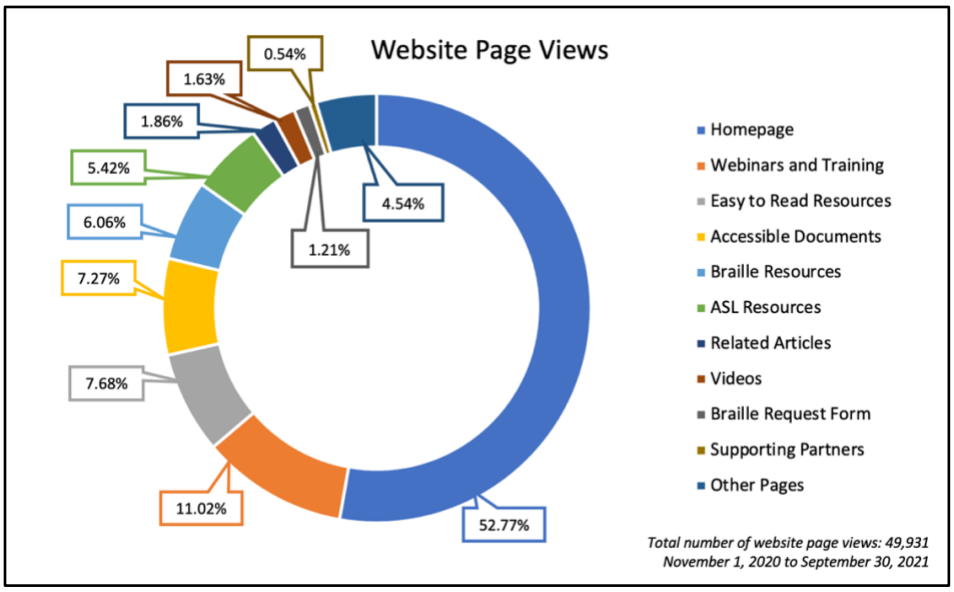
Dissemination of products and messages relies heavily on information and communications technologies (ICT) but encompasses other channels to reach some target audiences. The plan engages diverse partners in a multi-tiered network to optimize reach to as many people with disabilities as possible.

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.

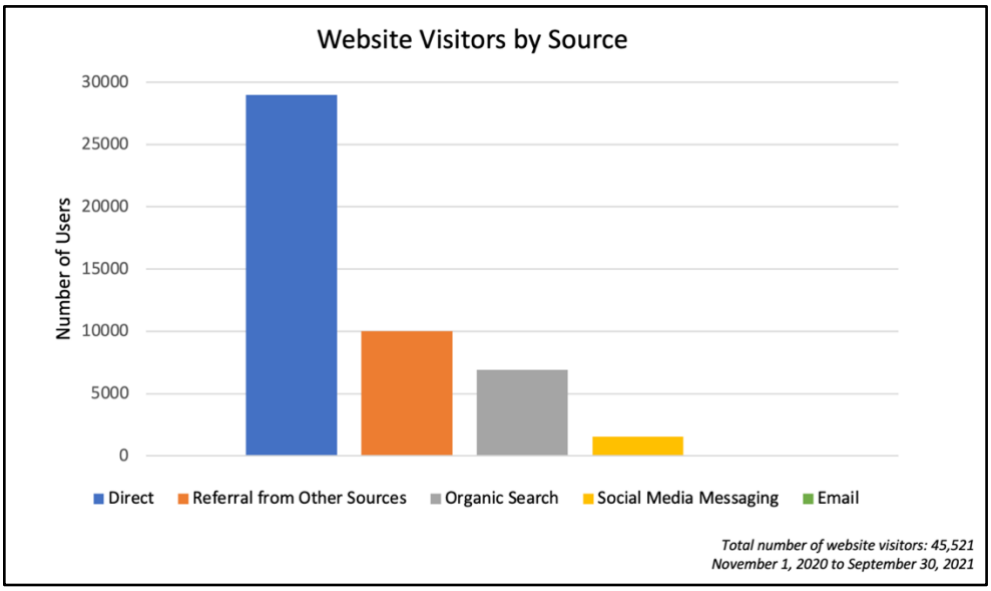
Three coalitions that focus on disability were recommended by the American Association on Health and Disability (AAHD), another project partner. The Friends of the National Center on Birth Defects and Developmental Disabilities (NCBDDD) is a coalition of organizations that support the work of NCBDDD. 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:

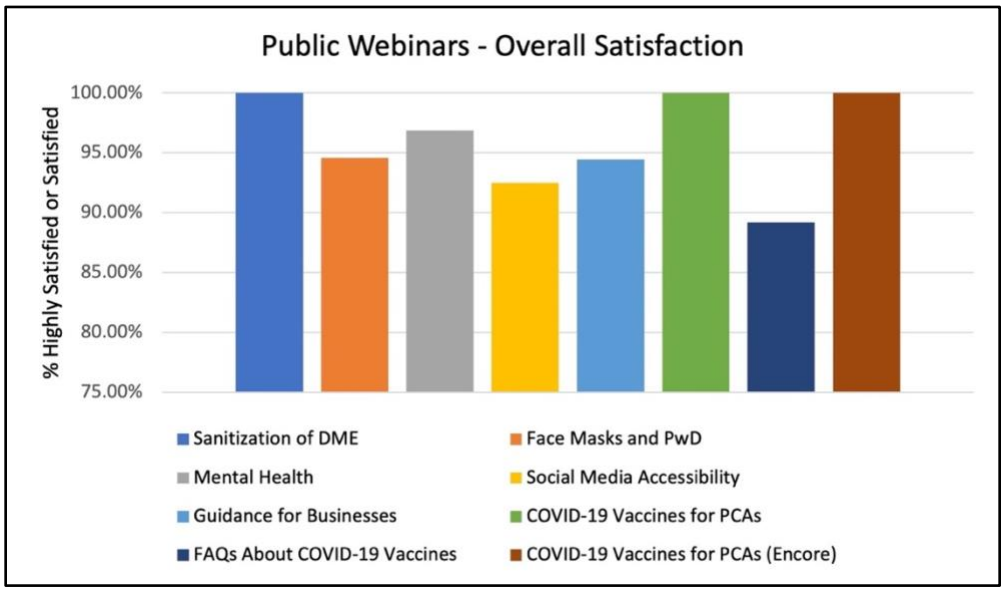
1. Website analytics
    - Number of unique visitors (by gender, age, location)
    - Total number of visits
    - Referrals from partner sites (and others)
    - Conversion rate (completed a transaction: viewed a product, downloaded a file, etc.)
    - Top 10 pages viewed
    - Video views
    - Demographics 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

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 and its project partners from the Center for Literacy & Disability Studies, Department of Allied Health Sciences, School of Medicine, University of North Carolina at Chapel Hill. 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.

REFERENCES

Agency for Healthcare Research and Quality (June 2014). *Quick-start guide to dissemination for practice-based research networks*. AHRQ Pub. No. 14-0051-EF. Retrieved August 19, 2020 from www.pbrn.ahrq.gov

Centers for Disease Control and Prevention. (2014). *National center for chronic disease prevention and health promotion's work group on translation knowledge to action framework, dissemination and engagement planning checklist.* US Dept of Health and Human Services. http://intranet.cdc.gov/nccdphp/home/WGOT/tools/index.html

Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability. *Disability and health data system (DHDS) data [2021]*. Retrieved June 18, 2021 from https://dhds.cdc.gov

Elsberry, L., & Mirambeau, A. (2015). *CDC evaluation coffee break: creating an effective dissemination plan*. Division of Heart Disease and Stroke Prevention, National Center for Chronic Disease Prevention and Health Promotion. Retrieved August 19, 2020 from https://www.cdc.gov/dhdsp/pubs/docs/cb_oct2015.pdf

National Federation of the Blind (2019). *The braille literacy crisis in America: facing the truth, reversing the trend, empowering the blind*. Retrieved September 7, 2020 from https://nfb.org//images/nfb/documents/pdf/braille_literacy_report_web.pdf

Schierle, M. (2019). *How to report metrics and build a performance culture: Fast load times*. Retrieved August 4, 2020 from https://web.dev/how-to-report-metrics/

Statistica (2021). *Percentage of people in the U.S. who had a disability from 2008 to 2019*. Retrieved August 4, 2020 from https://www.statista.com/statistics/792697/disability-in-the-us-population-share/

Assistive Technology Outcomes and Benefits
Volume 16 Issue 2, Summer 2022, pp. 127-134
 ISSN 1938-7261
Available online: www.atia.org/atob

Voices from the Field
The Importance of Braille During a Pandemic and Beyond

Johan Rempel, CVRT, CATIS, CPACC

Center for Inclusive Design and Innovation
College of Design
Georgia Institute of Technology

Corresponding Author
Johan Rempel
Center for Inclusive Design and Innovation
College of Design, Georgia Institute of Technology
512 Means Street
Suite 250
Atlanta, GA 30318
Email: johan.rempel@design.gatech.edu

ABSTRACT

In March, 2020, the same month that the World Health Organization (WHO) declared COVID-19 a pandemic, people throughout the United States and across the globe were required to rapidly make major decisions that impacted every aspect of their lives, including, but not limited to, social interactions, healthcare, transportation, childcare, education, and employment. In order to make the most informed decisions, it was critical during this period that all individuals be provided equal access to emergency-related information. Availability of essential health-related information can be even more critical for individuals who are blind, and who are often already disadvantaged due to a lack of available access in both the physical and digital environment.

This paper will explore the value and importance that braille serves in the lives of individuals who are blind and are proficient braille users. A qualitative study related to braille access for individuals who are blind was conducted by Center for Inclusive Design and Innovation at Georgia Tech in September of 2020, with a specific focus on access to COVID-19 materials. The findings of this qualitative study will be

examined, with a specific focus on how braille continues to serve as an essential format when accessing critical content.

Keywords: blind, braille, accessibility, embossed, braille-ready

THE IMPORTANCE OF BRAILLE DURING A PANDEMIC AND BEYOND

Technology continues to play an ever-increasing role in leveling the playing field for individuals with disabilities, and provides access to critical information that many individuals without disabilities may take for granted. This is certainly the case for individuals who are blind. The accessibility features built into many of the most common devices used today, such as the macOS and Windows operating systems, smartphones, and tablets, all contribute to a greater number of options available to individuals who are blind. Powerful third-party screen reading programs such as Job Access with Speech (JAWS) are able to provide auditory access to much of the content available to sighted individuals.

Amidst the tremendous advancements that have been made in the area of assistive technology solutions for individuals who are blind, it is easy for individuals and organizations to underappreciate and overlook the continued value that braille offers. After all, the braille system was developed almost 200 years ago, long before any modern-day technology was available (Biography, 2015). Far from being obsolete, braille continues to be an essential means for individuals who are blind when accessing critical information.

Personal Statement

Throughout my career as a Vision Rehabilitation Therapist, Orientation & Mobility Specialist, and Assistive Technology Instructional Specialist, I have observed firsthand how the benefits of braille access can empower individuals who are blind. As a braille instructor, it was evident that the continued practice and dedication of learning braille would eventually provide a means for braille users to access and retain information in ways that speech output alone could not.

TARGET AUDIENCE AND RELEVANCE

This article may be of value to educators and healthcare providers, including, but not limited to, direct service providers to individuals who are blind, and any researchers and/or organizations disseminating information to individuals who may require braille as their preferred means of accessing content. The findings in this article related to COVID-19 materials was subject to IRB approval.

LITERATURE REVIEW

Publications and data related to the use of braille and its relevance to individuals who are blind for accessing, learning, and retaining information will be reviewed. Sources of information include the following:

- National organizations serving individuals who are blind and who have low vision
- Research examining brain activity, cognition, and retention with individuals who are blind and who access braille
- Data collected by Center for Inclusive Design and Innovation (CIDI) at Georgia Tech through a qualitative study related to the need for COVID-19 materials in braille format.

UNDERSTANDING THE CONTINUED RELEVANCE AND IMPORTANCE OF BRAILLE

The National Federation of the Blind (NFB) estimates that approximately 10% of individuals who are legally blind (a visual acuity of 20/100 or less in the better-seeing eye with best conventional correction, or a field of view of 20 degrees or less) are braille readers (National Federation of the Blind, 2009, March 26). In Journal of Blindness Innovation and Research, the authors point out that the employment rate among individuals who are legally blind or visually impaired in the United States is at 37% in accordance with the study referenced in the article. In the same article, the authors go on to state that "for individuals who read braille on a weekly basis and used a white cane, the likelihood of being employed and receiving higher earnings was higher than those who did not use these tools" (Bell et al., 2015).

Braille represents more than just another means of accessing content for individuals who are blind. From firsthand experience of teaching braille for several years, I have witnessed braille students increase their ability to access, process, and retain information in ways that auditory input offered by screen readers could not. This would appear to be especially relevant for braille users requiring access to critical health-related information during a pandemic.

In recent decades, there has appeared to be a notable shift with the use of braille by educational institutions and organizations, moving instead toward what may be considered a less expensive option of providing access to content for individuals who are blind. Braille is certainly not the only way in which individuals who are blind can access content. These additional methods include the use of e-books, audiobooks, and screen readers (software applications primarily used by individuals who are blind that convert digital content such as text, buttons, links, and images containing alternative text into synthesized speech).

There are primarily two ways in which braille is produced for content that requires larger volumes of braille beyond short notes or brief labels:

- **Embossed braille:** a physical document (typically pages of sturdy paper, but sometimes on a label, card, or specialty substrate) with text translated into the raised dot patterns of braille.
- **Refreshable braille display:** one of a wide range of portable output devices (typically used with a computer or mobile phone) that uses retractable pins to display a single line of braille (up to 80 characters, depending on the device) which can be read with the fingers as embossed braille. These often interface with commonly used screen readers such as JAWS, NVDA, and VoiceOver, thereby converting audio output into refreshable braille.

Both of the methods listed above rely on braille translation software, which translates electronic documents into braille code. From these files, a refreshable braille display can present tactile braille, or a braille embosser can produce a hard copy on braille paper.

When considering the role that braille continues to play within the landscape of so many technologies that are improving access for individuals with disabilities, there appears to be a tendency to couch the topic of braille and various technology solutions into a binary choice, where one takes precedence over the other. In fact, the relationship between braille and emerging technologies is more nuanced; very often, one will complement and support the other. As an equivalent example to illustrate this point, individuals who are able to access content visually would find it unacceptable if they were restricted to only having access to digital and web-based content. Conversely, if sighted individuals were limited only to information audibly such as radio stations, podcasts, and audiobooks, that would be equally unacceptable. Such restrictive thinking toward access for individuals who are blind, in other words, to presume that only one format for consuming content should be enough, appears to be a frequent occurrence. Limiting a braille user and/or a screen reader user to one format over another would significantly limit how, when, and where, they may need to access content in the most effective means possible. For individuals who are deaf-blind, braille is also one of the only formats in which they can access text-based information, since the auditory output of screen readers alone would not meet their needs.

There is also a misconception that auditory means of access to content for individuals who are blind serves as an equivalent substitute for braille. Accessing content in a linear, auditory fashion lacks the tactile reinforcement of sentence structure and spelling that braille offers, or the ability to quickly scan and review information in a non-linear way that is an option readily available to sighted individuals.

One benefit to embossed braille is that it can be displayed across an entire page. This allows a braille user to quickly scan and review a single line or paragraph, or skim through an entire page and its sections, similar to the way that a sighted person can quickly skim through a page. Embossed braille also provides access to braille readers who may not have a refreshable braille display and/or screen reading technology.

One of the benefits to refreshable braille displays is that they allow digital content to be translated into braille quickly. However, one of the most significant restrictions to refreshable braille displays is that they only display a single line of braille at a time. Although refreshable braille displays are becoming less expensive as their use expands, they may also be cost-prohibitive for some individuals. Whether braille is being embossed or accessed through a refreshable braille display, it is also worth noting that there is frequently a manual process required for an accurate translation of the braille conversion, especially if the source of the digital content itself was not created with accessibility in mind.

The various ways in which braille is produced, and the number of ways in which it is accessed, continue to evolve since it was first invented almost 200 years ago. However, its fundamental value and importance

as a tactile format for individuals who are blind continues to remain relevant today. To understand its continued relevance, it is helpful to understand how it differs from other means of access for individuals who are blind, such as audio format. As stated in "The Importance of Braille Literacy" press release, "Braille is not a code to be deciphered but it is a method of reading and writing that is equal in value to print for sighted people." (The International Agency for the Prevention of Blindness, 2017).

QUALITATIVE STUDY OF COVID-19 RELATED CONTENT FOR BRAILLE USERS

CIDI conducted a qualitative study related to COVID-19 materials between September 10 and September 17, 2020, with a specific focus on individuals who are self-reported as being either legally blind or low vision, and who use braille on a consistent basis. The methods were reviewed by the Institutional Review Board (IRB) at Georgia Tech. Informed consent was acquired from the participants prior to beginning the study (Protocol H20315). All interviews were conducted remotely, partially due to geographic proximity, but also out of an abundance of caution during the COVID-19 pandemic. The WebEx platform was used to remotely interview all participants. Familiarity with the platform was provided to participants ahead of time to ensure a successful connection. The study carried out was a qualitative study that included six participants.

One of the goals of this assessment was to gather the needs and insights related to existing COVID-19 content, and to investigate the existing need for alternative format development for braille users. All the braille users recruited for this study met the following criteria:

1. 18 years and older
2. have blindness or low vision and use braille for reading
3. read in English
4. currently living in and present in the U.S.
5. have access to the internet, a computer, and their respective assistive technology solutions needed for remote testing.

The term "blindness" referred to in this study is more in alignment with legal blindness, as opposed to denoting an absence of any sight. The definitions of "low vision" can differ considerably, depending on the organization and potential funding services and standards of service. For the purposes of this study, low vision was defined as the inability to read regular-size print effectively with the use of corrective lenses, which may result in the need, and use, of braille by an individual. Beyond a particular individual's visual acuities and overall functional vision, the goal of this study was to collect feedback from individuals who use braille as one of their primary means of accessing content.

A concerted effort was made to include participants from a variety of geographic areas in the United States, and with varying backgrounds and experiences. The backgrounds included students, teachers, administrators, and librarians. CIDI's recruitment outreach included several statewide and national organizations that employed and/or served individuals proficient in braille. CIDI also extended recruitment

efforts to its individual consumers who were braille users. Participants for this study included representation from the following states: Georgia, Texas, Maryland, and the District of Columbia. The ages of participants ranged from 25 through 74. A summary of questions and feedback collected from participants included the following:

- assistive technology used for accessing the internet and computer
- suggestions for COVID-19 materials in order to improve their accessibility
- whether or not participants would benefit from, and use, embossed (printed) braille for COVID-19 related materials if it was made available
- alternative accessible formats to consider with COVID-19 related materials.

USE OF ASSISTIVE TECHNOLOGY

All participants owned computers (laptop or desktop) and smartphones. The participants stated that they used both their computers and smartphones to access the internet. All six participants were iPhone users, and used the built-in screen reader, VoiceOver, on a regular basis. All participants also had access to refreshable braille displays. All participants used the JAWS screen reader software to access the internet and their computers. Three participants stated that they occasionally used the NVDA screen reader software. These findings in and of themselves are not especially surprising. According to a WebAIM survey from May through June of 2021, 84.8% of screen reader users rely on either JAWS (53.7%) or NVDA (30.7%). All of the participants in the qualitative study also reported using the VoiceOver built-in screen reader available in the iOS operating system.

The Use of Embossed Braille for COVID-Related Materials

All six participants reported having access to a refreshable braille display. Especially noteworthy is the fact that all of the participants stated that they would use embossed braille versions of COVID-19 related materials if this was made available to them. It was expected that there would be a need for embossed braille among some of the participants. However, the unanimous consent for this expressed need by all six participants to have access to braille-embossed COVID-19 related materials suggests that the need for braille was even greater than originally anticipated. This unanimously expressed need for embossed braille was even more telling, considering that they all had access to a refreshable braille display and screen reading technology. Two participants in particular stated that understanding and retention is improved for them when utilizing embossed braille. One participant also stated that it is faster to read a printed braille version of the material than to use a screen reader. The fact that a refreshable braille display only conveys one line of digital braille at a time, and is also dependent on a power source, appears to further influence the value and importance of embossed braille for participants. For instance, one participant specifically mentioned the convenience of embossed braille without having to rely on additional technologies while accessing it.

Additional Formats Specified by Participants

Some of the participants also expressed that the need for COVID-19 related materials be made available in accessible PDF and Word formats. These additional formats would also allow easier overall access

and a cleaner conversion to embossed braille when used by those with access to a braille embosser (device that converts digital text into embossed braille). One participant emphasized that they may be reproducing COVID-19 materials on an embosser for other braille users, and doing so would not be possible without accessible source files such as Word or PDF.

CONCLUSION

The feedback received from participants through the qualitative study emphasizes the continued value and importance of braille for braille readers, especially when accessing critical information such as COVID-19 resources during a pandemic. Although the sample size of six in this qualitative study was relatively small, a great deal of valuable data was gleaned from such a sample size.

Technology has undoubtedly had a major impact in leveling the playing field for individuals with disabilities. However, this does not negate the significance and importance that braille continues to have in the lives of people who are blind and low vision. Assistive technology solutions such as screen readers and refreshable braille displays that work in conjunction with one another should be viewed as supplementing, not replacing, braille. Providing critical information such as COVID-19 resources in embossed braille during a pandemic, along with additional alternative formats leveraged by various assistive technology solutions, is essential. The availability of content in braille format further empowers braille users to effectively access critical information in order to make the necessary decisions for themselves and their loved ones, a process that individuals without disabilities may easily take for granted.

DECLARATIONS

The findings and conclusions in this report are those of the author(s) and do 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.

RESOURCES

Bell, E. C., & Mino, N. M. (2015). Employment outcomes for blind and visually impaired adults. *Journal of Blindness Innovation and Research, 5*(2). https://nfb.org//images/nfb/publications/jbir/jbir15/jbir050202.html

Biography (2015). *Louis Braille.* https://www.biography.com/scholar/louis-braille

National Federation of the Blind (2009, March 26). *The braille literacy crisis in America: facing the truth, reversing the trend, empowering the blind* [Report]. Jernigan Institute. https://nfb.org/images/nfb/documents/pdf/braille_literacy_report_web.pdf

The International Agency for the Prevention of Blindness (2017). *The importance of braille literacy* [Press release]. https://www.iapb.org/news/press-release-the-importance-of-braille-literacy/

WebAIM (May–June, 2021). *Screen reader user survey #9 [Data set]* https://webaim.org/projects/screenreadersurvey9/