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BY KRISHNA VENKATASUBRAMANIAN, TINA-MARIE RANALLI, PRIYANKAN KIRUPAHARAN, AND LIAM CANNON

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# Considering Trauma in Accessible Design for Adults with Intellectual and Developmental Disabilities

*Applying the principles of trauma-informed care when designing apps can improve accessibility for people with intellectual and developmental disabilities.*

There are more than seven million people in the U.S. with intellectual and developmental disabilities (I/DD).<sup>28</sup> I/DD is an umbrella term often used to describe a diverse set of disabilities that affect a person's ability to learn, reason, understand abstract concepts, problem-solve, and engage in everyday social and life skills. I/DD appear in childhood and are likely to be present throughout life.<sup>1</sup>

In the past, this community has often been left behind in gaining access to the latest computing technologies. However, a 2016 survey on the use of smartphones and tablets by people with disabilities found that people with I/DD were increasingly adopting smartphones and tablets.<sup>27</sup> Our prior work, conducted in the past few years with adults in this community, also yielded similar results.<sup>38</sup> It is therefore the right time to explore novel, smart-device-based computing apps that meet the needs, wants, and aspirations of the I/DD community.

## Key Insights

- In the U.S., an increasing number of people with intellectual and developmental disabilities (I/DD) are using smart devices. Therefore, apps for these devices should be designed to be I/DD-accessible.
- People with I/DD are highly likely to have experienced trauma in their lives and often have limited means of dealing with its lasting effects. Designers should therefore consider trauma when designing I/DD-accessible apps.
- To this end, we argue for applying the principles of trauma-informed care to computing and app design.

Ideally, apps for the I/DD community should be designed to be I/DD-accessible, which we define as designed in collaboration with this community to meet the requirements of its very diverse members. In recent years, research has looked into how to make apps I/DD accessible. These efforts have revealed several design suggestions, including:

- Providing content in the form of images, interactive content, and videos<sup>10</sup>
- Using concrete, big, differentiated icons and symbols<sup>5</sup>
- Gamification of content<sup>35</sup>
- Accommodating different levels of literacy with written content<sup>8</sup>
- Using positive reinforcement when a user successfully engages with the content.<sup>22</sup>

In this article, we posit that, in addition to these accessibility guidelines, designers should include an additional consideration: *trauma*. Further, we focus our discussion on the needs and desires of *adults* within the I/DD community. Therefore, when we use the terms *people* or *individuals with I/DD*, we explicitly mean adults with I/DD.

HCI and accessibility research have not significantly addressed the needs of the I/DD community. A 2021 research paper showed that I/DD was one of the least addressed communities in accessibility research.<sup>24</sup> Of the more than 500 papers in accessibility research published at the ACM ASSETS and CHI conferences between 1994 and 2019, only 2.8% mention I/DD and only 1.6% focus exclusively on I/DD.<sup>24</sup> These statistics are even worse when we look at the I/DD community through the lens of trauma. To the best of our knowledge, work at the intersection of I/DD and trauma is virtually nonexistent in HCI and its allied domains. Over the past five years, our team has been working with the I/DD community to better understand the needs of this community and to co-design smart-device-based computing apps with them, specifically apps that relate to helping adults with I/DD to independently manage trauma and abuse.<sup>17, 36, 37, 38</sup> It is based on this experience that we argue for considering trauma when designing I/DD-accessible apps.

### Why Is Considering Trauma Relevant?

Trauma is defined as a sudden, potentially deadly experience that often leaves lasting, troubling memories.<sup>11</sup> In the U.S., a significant number of people with I/DD are highly likely to have experienced trauma,<sup>18</sup> for several reasons:

- *Rampant abuse*: The abuse of people with I/DD in the U.S. is at epidemic proportions. In 2018, National Public Radio, based on a Bureau of Justice Statistics' report from 2017 (the last year for which such statistics exist), reported that people with I/DD are sexually assaulted over *seven times* more often than people with no disability.<sup>30</sup> (The rate of violent victimization for people with I/DD is the highest among people with any disability and is over four times the rate for non-disabled people.<sup>14</sup>) Further, among individuals with disabilities who reported abuse, more than 90% experienced abuse on more than one occasion and 46% experienced abuse more frequently than they could count.<sup>3</sup>
- *Voicelessness*: The voices and opinions of people with I/DD are often discounted.<sup>3</sup> This negation of the reality and lived experiences of people with I/DD is another cause of trauma in their lives.<sup>6</sup>
- *Highly managed lives*: People with I/DD often lead highly managed lives in terms of where and with whom they live, what they do with their time, and how they spend their money.<sup>23</sup> This means they often lack control and flexibility over their own environment and how they use their time—yet another source of trauma.<sup>36</sup>

There are no clear statistics on what percentage of people in the I/DD community have experienced trauma; in fact, a 2019 paper indicated that there was a lack of research on trauma among people with I/DD. This study also established that a broad range of adverse life events have the potential to be traumatic, cited differences in how symptoms manifest, and identified behavioral symptom equivalents to post-traumatic stress symptoms.<sup>32</sup>

Trauma affects people with I/DD in profound ways, such as:

- Impaired working memory for tasks at hand
- A variety of negative mental side effects (for example, depression and anxiety) that vary among individuals
- Excessive distraction, even more so than non-I/DD individuals experience
- Limited ability to avoid triggers<sup>a</sup> due to having less control over their environment than those without I/DD (for example, a group living situation).

All of these experiences are made worse by the limited ability of individuals with I/DD to get appropriate help to manage the negative effects of their trauma.<sup>40</sup>

Therapeutic treatment, such as cognitive behavior therapy (CBT) and eye-movement desensitization and reprocessing (EMDR), have been shown to be effective for people with I/DD.<sup>26</sup> There are often substantial systemic and personal barriers, however, that prevent or impede people with I/DD from accessing therapy to deal with their trauma,<sup>39</sup> including:

- A *lack of therapists* who will work with people with I/DD
- Frequent *diagnostic overshadowing* by therapists and providers, where the negative effects of trauma (for example, anxiety, depression, complicated grief) are seen as merely an aspect of the person's I/DD and/or other disability
- A *lack of knowledge about mental health issues* among people with I/DD
- *Logistical difficulties* related to the lifestyles of people with I/DD, such as a lack of suitable transportation and a lack of privacy in group living situations, which often preclude them from pursuing therapy.<sup>39</sup>

Since trauma is quite common among the I/DD community and they generally have limited means of dealing with its negative effects, it is crucial that apps designed for the I/DD community be designed with this in mind. In the next section, we describe several ways of doing so.

### WHAT IS DIFFERENT ABOUT THE I/DD POPULATION?

The American Association of Intellectual and Developmental Disabilities defines I/DD as a set of disabilities that negatively affect the trajectory of an individual's intellectual, emotional, and/or physical development.<sup>1</sup>

The consequences of experiencing I/DD are not just cognitive. Like all abilities labeled "disabilities," I/DD have social consequences for the people who experience them. It is well known that having a disability affects the way in which society interacts with and treats individuals with disabilities as well as how they experience life.<sup>25</sup> The same is true for members of the I/DD community. They too continue to experience unique challenges in life, which makes their needs qualitatively different from those of individuals with other disabilities. These challenges include:

- *Isolation and infantilization*: Individuals with I/DD often lead isolated lives, away from family and friends in group homes.<sup>12</sup> They are often infantilized by people around them and not believed, especially if they complain about their situation.<sup>3</sup>
- *Limited education and financial prospects*: Often individuals with I/DD do not receive formal education or enough education to survive in today's world. This means that literacy levels in the I/DD community are often low, which then limits their employment and financial prospects in life.<sup>9</sup>

- *Limited community integration and participation:* People with I/DD often have limited social experiences (for example, they are held back by parents or other caregivers) in the name of safety. This in turn increases the barriers individuals with I/DD encounter to participating in communities of their choice. The limitations on their social encounters affect their ability to interact socially, understand the nuances of language, and comprehend the cultural meanings of things around them.<sup>9,12</sup>
- *Reduced self-determination:* Many individuals with I/DD often have limited self-determination, which reduces their ability to procure good healthcare, participate in intimate relationships, and even exercise their reproductive rights.<sup>9</sup>

Further, people with I/DD may have additional impairments in addition to I/DD, such as speech or motor impairments, which can complicate and exacerbate the aforementioned experiences.

It is well understood that accessibility design often leads to innovation.<sup>31</sup> Therefore, we believe that thinking about accessibility for I/DD offers a perspective that can deepen our understanding of the downstream effects of all the apps that we build. Designing for the I/DD population will allow us, as designers, to better understand the trade-offs that our design decisions bring about, which benefits all of design—even in non-I/DD and non-disability contexts.

## Considering Trauma in Design

We now offer our ideas on how to approach designing for individuals with I/DD, with trauma in mind. We ground our work in the framework of *trauma-informed care (TIC)*. TIC is an idea from social work practice used by organizations to support traumatized individuals. The U.S. Substance Abuse and Mental Health Services Administration (SAMHSA) qualifies that any organization seeking to provide TIC services must satisfy five core criteria: safety, trust, choice, collaboration, and empowerment.<sup>15</sup> These criteria were originally defined for the general population of trauma survivors. In the past decade, however, they have been seen as applying to the I/DD community as well.<sup>20</sup> The idea is that trauma-informed I/DD services should enable a traumatized person with I/DD to feel emotionally and physically *safe*, *trust* those helping them, have a *choice* in deciding what helps them, be able to *collaborate* with others (on a level playing field) toward their personal well-being, and be *empowered with sufficient knowledge* about trauma to act.<sup>20</sup>

TIC can be thought of as a novel paradigm in inclusive design for I/DD accessibility. In recent years, several approaches to inclusive design for adults with I/DD have been developed, generally based on the notion that people with I/DD are *experts by experience* and focused on including people with I/DD in the design process in some way.<sup>34</sup> These approaches differ in *how* the expertise of individuals with I/DD is incorporated into the design process, including those that focus on:

- The person-specific abilities of individuals with I/DD<sup>33</sup>
- Performing co-design with an advisory panel of people with I/DD<sup>34</sup>
- Having individuals with I/DD interact with one another as a way to explore design options<sup>2</sup>
- Using active support, which offers a way for designers to participate more self-consciously as facilitators in co-designing with people with I/DD.<sup>4</sup>

These approaches share similarities with some TIC principles, such as choice and collaboration. However, TIC not only assigns different valences to these principles but also adds additional trauma-specific elements, as we shall see below.

In the rest of this section, we discuss recommendations that show how these TIC criteria can be adapted to the design of I/DD-accessible apps by exploring important design guidelines related to each criterion. To this end, we provide four broad recommendations.

**Recommendation 1: Partnering with self-advocacy organizations within the I/DD community who work with trauma survivors.** An integral part of designing I/DD-accessible apps is having an understanding of what people with I/DD experience post trauma. Consequently, we suggest that designers seek out and partner with self-advocacy organizations, which often have extensive experience working with trauma survivors, during their design process. *Self-advocacy organizations* are institutions that advocate for people with I/DD and help them take control of their lives.<sup>13</sup> These organizations conduct their advocacy through *self-advocates*, individuals with I/DD who have extensive knowledge of the diverse needs of different members of this population, including people who have experienced trauma and the different kinds of aftereffects thereof. Further, self-advocates are trained to represent their community by articulating their thoughts, feelings, and experiences, and providing information about the various needs of the larger I/DD community.

Over the past decade, people with disabilities have increasingly been included in the design of technology intended to be accessible for their population.<sup>4</sup> However, their role is often limited, especially when it comes to the I/DD community. Designers typically cite ethical reasons for restricting the involvement of people with disabilities. For instance, designers often feel they cannot presume to know whether the population is capable of understanding technical designs, providing consent to participate, and being recruited for research studies; or whether they're capable of talking about triggers and the negative effects of trauma. Despite any good intentions, this protectionism in the name of ethics is both paternalistic and discriminatory.<sup>19</sup> Of course, not every survivor with I/DD is ready, willing, or able to discuss their experience with the aftereffects of trauma. In our experience, however, working with self-advocates who are survivors greatly increases the chance of finding such individuals since, given nature of their advocacy work, self-advocates have already consented to and are capable of discussing their trauma. Working with self-advocacy organizations would therefore automatically foster researchers' access to individuals with I/DD who can participate in design efforts and user studies, thereby giving them greater access to ideas and methods on how best to engage with people with I/DD.

Our research group has considerable experience successfully partnering with I/DD self-advocacy organizations and centering in our research self-advocates who have experienced trauma. For five years and over the course of several projects, our research lab has worked with I/DD self-advocates who are survivors of abuse. In our experience, these self-advocates not only teach designers about the needs and lived experiences of the I/DD community post trauma, but they also make excellent design partners. They can aid in the entire design life cycle—from ideation to refining the eventual artifact—of any technology being built. This work with self-advocates also organically fulfills one of the fundamental requirements of working with people with disabilities: *nothing about us without us*, which is especially important to the I/DD community.<sup>16</sup>

In pursuing our research, we have found that one of the most important things researchers should do when working with self-advocacy organizations is to work to consciously *build and sustain trust between the researchers and self-advocates* throughout the collaborative process. To this end, some of the strategies that have worked for us include:

- Showing the self-advocates that we highly value their opinions
- Being transparent about where and how the self-advocates' input is used
- Explaining our decision making to clarify which ideas can be acted on and which cannot
- Working hard to clearly state that not acting on an idea does not indicate anything about the quality of the idea.

By partnering with I/DD self-advocacy organizations and collaborating with self-advocates in designing apps, we essentially address the *trust* criterion of the TIC framework, as eventual users of the app (individuals with I/DD) can be confident that it has been designed with their interests at heart.

**Recommendation 2: Understand the diversity of the I/DD community beyond disabilities and be aware that potentially anything can trigger someone.** It has been noted that, as

a population group, people with I/DD can be considered their own cultural group, as opposed to just being considered individuals from the larger population who have I/DD.<sup>7</sup> Thus, when designing I/DD-accessible apps, designers should consider the varied lived experiences across the I/DD community, *in terms of both differing abilities and intersectionality* (for example, differences in experiences based on considerations like race, gender identity, sexual preferences, native language, and socioeconomic status). An app that does not actively represent a worldview supportive of the diversity of people with I/DD essentially rejects non-normative body and mental states, which is oppressive and traumatizing.<sup>29</sup> A simple example of considering the lived experiences of people with I/DD could be to include more than just stereotypically cisgender male and female voices in text-to-speech systems. One can imagine having options that include not only voices of people with I/DD but also those of transgender and nonbinary members of this community.

Further, as stated above, individuals with I/DD often have a limited ability to get appropriate help to manage the negative effects of their trauma. App designers should therefore be proactive about minimizing potential triggers and incorporating into their designs one or more ways for users to manage becoming triggered while using the app. Perhaps a way for us, as designers, to think about a user being triggered could be modeled on *exception handling*. In short, designers of I/DD-accessible apps should take two things into consideration:

- *Anticipation*: Try to anticipate the common ways in which a person can be triggered. This requires consciously checking one's assumptions about users and what could trigger them. For example, consider meditation apps, which often unproblematically tell users to close their eyes before starting the practice. However, for people who have experienced trauma, closing one's eyes is often triggering.<sup>36</sup> Thus, an I/DD-accessible app should explicitly provide users with options for various safety measures that can be taken before and/or during a meditation, such as keeping their eyes open or first checking that the doors are locked, to make sure they feel safe and in control of their surroundings. Unless users first feel safe and in control, it is highly unlikely that they will be able to fully participate in and benefit from any kind of meditation or mindfulness exercise.
- *Diversion*: Provide one or more means of helping the user if they do become triggered. In other words, the design itself could, among other things, offer welcome diversions or allow users to easily take a break from the app to clear their head. As part of any app designed for the people with I/DD, such diversions might include suggestions for offline activities tailored to the lifestyles of people with I/DD. That said, apps should *not* suggest activities that would require being able to independently travel to another location (for example, the local museum) because it is something people with I/DD are often unable to do.

By proactively designing to reduce triggers and provide options for users to cope if triggers do occur, we are satisfying the *safety* criterion of the TIC framework, which ensures that the individuals with I/DD feel comfortable using the app as much as possible.

**Recommendation 3: Allow users to consume the app's content beyond the purely visual by adding narration.** In our experience, individuals with I/DD often find that reading the written content in apps requires quite a high cognitive load. This is even worse for individuals with I/DD who have experienced trauma, given their propensity for excessive distraction and their impaired working memory. Consequently, I/DD-accessible apps should make content easy to consume. A lot of prior work in this domain focuses on providing information visually. However, it is not always possible to represent complex ideas in a purely visual manner. One may be tempted to include written text to go with the visual but, as mentioned, such accompanying text can be problematic due to the high cognitive load that even simple reading can present for the I/DD community.

Based on the input we received from community members, an essential option that app designers should offer is narration, which greatly contributes to minimizing users' cognitive load.<sup>37</sup> The idea behind narration is to implement audio that describes or even reads the contents of a given screen in the app. However, this should go beyond what screen readers do for those with vision impairments (that is, read the alt-text of images and the text on the screen) and provide a variety of additional context about the content on the screen. For example, narration can be used in a video to describe the background of a story being depicted, where the background is not explicitly shown in

the video. Narration, as we conceive of it, is thus a way to serve the app's visual content to the user via another auditory medium. Narration, though, is not currently a common feature of app design, and is typically limited to specific contexts, such as describing elements that lack visual representation. This needs to change when designing for individuals with I/DD: Narration should accompany even the visual elements in apps. Such narration can help our population in at least three ways:

- *Improved comprehension:* Unlike a screen reader, which simply reads the exact contents of the screen, narration can provide context for the app's content. Narration can more closely resemble the narratives we read and the speech we hear, for instance, by adding transitional phrasing between screens/sections to express the flow of content, making it easier to understand. Narration can also guide the user through an app in a structured manner. We have discovered that individuals with I/DD find it easier to follow along if the narration has a consistent narrative flow, clearly conveying the beginning, middle, and end of the content on the screen.<sup>37</sup> The narration should also include pauses at appropriate intervals, which lends it a more natural flow and gives the individual more time to process the information—allowing people time to process things is very important for the I/DD population.
- *Immersive experience:* Narration immerses the individual in the app by letting the user more passively listen to the content rather than expending cognitive energy to visually parse and then absorb it. Engaging the auditory sense adds an additional layer of sensory input to the user experience that makes the individual feel more engaged with the app and makes it easier to maintain focus, while also decreasing the cognitive load.
- *Inclusive experience:* Since I/DD includes a very broad set of impairments, being able to cater to a variety of cognitive processing levels is essential. An app narrated in a natural and conversational tone, with wording commonly used in colloquial language and using transitional phrases, can help users to feel included as one of the populations for whom the app is expressly designed. Last, when combined with a narrative voice from the I/DD community, the presence of narration can foster an increased sense of community and belonging for users with I/DD.

A well-designed narration system satisfies the *collaboration* criterion of the TIC framework by making the app appear conversational in nature. This conversational design mimics the feeling of interacting with someone with a similar background—a peer, which can have its own benefits, given the general isolation of this community. Further, the presence of narration also satisfies the *empowerment* criterion of the TIC framework, as it provides additional information and context about the content of the app, thus empowering individuals with I/DD to use it in ways that best fit their needs.

**Recommendation 4: Ensure that any measures to manage users' choices within the app are trauma-aware.** Trauma often causes people with I/DD, who already do not have much control over their lives, to lose their sense of control over their lives and bodies. It also affects the cognitive state of people with I/DD by affecting their working memory and making them especially prone to distractions. Further, as the number of features in an app increases, so does the complexity of the app in terms of the number of choices that need to be managed, not only for the designers but also for the eventual users. We contend that designers of I/DD-accessible apps should try to develop ways for the app to suggest or organize the choices available to the user, with the goal of giving them more control and reducing their cognitive load.

One way to increase the user's control over the choices within the app would be to design apps in accordance with the maxim: *Nothing in the app is mandatory*. That is, a user should be allowed to skip any feature, content, or activity within the app. For instance, though earlier we discussed the importance of narrated content, users should be able to turn it off if they do not feel like listening to the narration on a particular day.

The larger the number of choices within the app, the more important it is to manage the cognitive load on the user, for instance, with an integrated recommender system. Of course, care needs to be taken in the design of any recommender system. Given the negative effects of trauma on individuals with I/DD, the recommender system may have to considerably limit the number of choices available.

A careful deployment of the power of defaults (based on an understanding of people with I/DD post trauma) can play a big role in reducing the number of choices through which the user needs to be guided. And any recommender system should be careful to only make suggestions when guiding the user through the available choices and *not* dictate what the user should do. This non-dictatorial approach should extend beyond helping users navigate the selection of options to the language and prompts used in the app as well.

Explicitly maximizing the user's ability to make their own choices in I/DD-accessible apps while minimizing the cognitive load of selecting options in a trauma-informed manner satisfies the *choice* criterion of TIC.

## Conclusion

Adults with I/DD in the U.S. are increasingly using smart-device-based computing apps. Much of the existing work on designing apps for this community has focused on simplifying the language in the app and including visual and interactive elements in the content. Here, we argued that, in addition to these guidelines, we need to consider the surprising prevalence of trauma in the lives of people with I/DD. To this end, we presented four broad recommendations for designing these apps in a trauma-informed manner, including collaboration with self-advocacy organizations, recognizing that any design choice can be triggering, incorporating narration, and providing users with trauma-aware choices. By following these principles, the computing field will be better positioned to design for the needs of this otherwise extremely underserved group.

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Krishna Venkatasubramanian is an associate professor of computer science and the director of the Accessible and Socially Responsible Technologies (ASSET) Lab at the University of Rhode Island.

Tina-Marie Ranalli is an independent consultant and researcher based in Providence, RI. She earned her Ph.D. from the University of Pennsylvania.

Priyankan Kirupaharan is currently pursuing a Ph.D. in computer science at the ASSET lab at the University of Rhode Island.

Liam Cannon is currently pursuing an M.S. in computer science at the ASSET lab at the University of Rhode Island.

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