Designing Post-Trauma Self-Regulation Apps for People with Intellectual and Developmental Disabilities

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ABSTRACT

In the US people with intellectual and developmental disabilities (I/DD) comprise one of the most likely groups to experience traumatic life events. These experiences often produce negative effects (e.g., stress, anxiety, grief, numbing, etc.) that need to be managed. Methods such as emotional self-regulation are often used to help people cope when these effects present themselves post-trauma. In recent years mobile-computing-devices-based apps have been increasingly used to help the general population with autonomous self-regulation. However, none of these is designed for people with I/DD or is cognizant of the trauma they experience in their lives. We interviewed eight (8) practitioners at a trauma services organization that, among other things, helps people with I/DD learn and practice post-trauma self-regulation. The goal of the interviews is to understand what it would take to build post-trauma self-regulation apps for people with I/DD. Based on the interview responses we argue for a set of guidelines, based on the social work practice of trauma-informed care, to design post-trauma self-regulation apps for people with I/DD.

CCS CONCEPTS

• **Human-centered computing** → **Accessibility technologies**.

KEYWORDS

trauma-informed care, intellectual disability, developmental disability, trauma, design

1 INTRODUCTION

Trauma is a sudden, potentially deadly experience that often leaves lasting, troubling memories [25]. In the US, a significant number of

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people with intellectual and developmental disabilities (I/DD)[1] are suspected to have experienced trauma in their lifetime [51]. The *negative effects of trauma* (e.g., anxiety, depression, complicated grief) experienced by people with I/DD are often misdiagnosed because of what is known as *diagnostic overshadowing*, where health practitioners assume that the negative effects of trauma are merely an aspect of the person's I/DD and/or other disability [50]. Therefore, the majority of people with I/DD who experience trauma may not get appropriate help to cope with the negative effects of the trauma and to improve their quality of life [86]. Moreover this disregard for, and negation of, the post-trauma reality of people with I/DD may also constitute another traumatic event, thereby re-traumatizing them [12]. Untreated trauma can result in severe and long-term impairments that negatively affect one's general well-being and emotional, social, academic, and physical development [51]. Therapeutic treatment often involves processing the traumatic experience. The methods to do so include, cognitive behavior therapy (CBT) and eye movement desensitization and reprocessing (EMDR), both of which have been shown to be effective for people with I/DD [50], especially EMDR [51]. However, there are often substantive systemic and personal barriers that prevent or impede people with I/DD from accessing the relevant mental health services [84]. Engaging in self-regulation - coping with the negative effects of trauma (more on this in Section 1.1) - outside of therapy has been shown to play a major role in facilitating the process of recovering from trauma in people with I/DD [51]. *It is, thus, important to empower people with I/DD by giving them the means to autonomously cope with the negative effects of trauma in their daily lives, that is, self-regulate, whether or not they also pursue therapeutic treatment.*

The last two decades have seen the near pervasive availability of *mobile computing devices* (e.g., smartphones, tablets, and wearables). Such mobile computing devices are increasingly being used to help people who have experienced trauma autonomously cope with the day-to-day negative effects of trauma. In the past decade, the US federal government has developed several trauma-focused apps that help military veterans and US-Department-of-Defense-affiliated military and civilian personnel seek help, understand, and manage the negative trauma effects they experience [58, 61, 68, 81]. However, to the best of our knowledge, no *post-trauma self-regulation (PTSR)* app exists that has been specifically designed for the needs of people with I/DD. Recent years have seen the regular use of mobile computing devices (like smartphones, tablets, etc.) by people

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[1]Based on the definition from the American Association of Intellectual and Developmental Disabilities, I/DD can be thought of as a set of disabilities that negatively affect the trajectory of an individual's intellectual, emotional, and/or physical development. I/DD appear in childhood and are likely to be present throughout life [1].

with I/DD in the US [56, 80]. Therefore a mobile-computing-device-based app would provide an excellent mechanism for empowering people with I/DD to self-regulate post-trauma. In this collaborative paper, which was written by an HCI and a humanities scholar, we **aim** to explore the design of post-trauma self-regulation apps for people with I/DD that can complement therapeutic interventions.

Consequently, in this paper we first define the notion of self-regulation in the context of its use by people with I/DD. We then present an interview study where we interviewed eight (8) *practitioners* at an organization in the United States (US) that provides trauma services specifically for people with I/DD. As part of their services, among other things, they teach people with I/DD how to use self-regulation to cope with trauma. Such efforts are intended to be complementary to any therapeutic interventions that the survivor may pursue. Our aim with the user study is to understand the following: (1) What does post-trauma self-regulation for people with I/DD entail? (2) Do people with I/DD use apps/technologies for post-trauma self-regulation and if so, how? and (3) What should designers keep in mind when designing post-trauma self-regulation apps for someone with I/DD?

We then present a new framework for designing for post-trauma self-regulation that leverages the notion of *trauma-informed care* [46]. Trauma-informed care was originally developed in the field of social work for support organizations that help trauma survivors. The practice of trauma-informed care avoids pathologizing trauma and focuses on validating the post-trauma experiences of the individual. This prevents retraumatization of the individual while empowering them to develop a sense of safety and reducing any shame or guilt surrounding their past trauma [39]. *In this paper, we reflect on how the notion of trauma-informed care can be applied to the design of PTSR apps for people with I/DD and propose several design guidelines to this end.*

This paper makes the following **contributions**: demonstrating the lack of existing self-regulation solutions that meet the PSTR needs of people with I/DD (Section 2); an interview study with stakeholders to understand what to keep in mind when designing PSTR apps (Section 3); and proposed guidelines for designing PTSR apps for individuals with I/DD (Sections 5).

1.1 Trauma and post-trauma self-regulation for people with I/DD

Before we delve into the details of designing post-trauma self-regulation apps, we present a short overview of how trauma affects people with I/DD. Trauma affects people with I/DD in profound ways. After trauma, people with I/DD can experience: (1) impaired working memory for tasks at hand; (2) a variety of negative effects from the trauma (e.g., depression, anxiety, etc.) that vary from individual to individual; (3) excessive distraction, even more so than non-I/DD individuals experience; (4) limited ability to avoid triggers[2] because of limited control over their environment than those without I/DD (e.g., a group living situation); and (5) limited ability to get appropriate help to manage the negative effects of their trauma [86].

The negative effects of trauma on an individual with I/DD need to be managed on an on-going basis. In this work, we do not look at the negative effects of trauma from a medical, diagnostic standpoint that seeks to determine the presence/absence of post-traumatic stress disorder (PTSD). Rather we approach the post-trauma state from the standpoint of what some humanities scholars term *dis-ease* [14, 72, 77]. This state of *dis-ease*, or a lack of ease, can present itself in many ways, including: a general sense of grief, depression, anxiety, sleep disturbance, exaggerated tendency to startle, self-harming behavior, and being stressed by triggers [51]. We do not view the state of *dis-ease* as something caused by triggers alone, though triggers can provoke or exacerbate it.

Note that we do not claim that self-regulation should be the only source of dealing with post-trauma *dis-ease* for people with I/DD. Therapeutic approaches, such as cognitive behavior therapy (CBT) and eye-movement desensitization and reprocessing (EMDR), are powerful, have been shown to work for people with I/DD [51], and are indeed useful. That being said, when it comes to the I/DD population, there is also a need to think more holistically beyond therapeutic approaches alone. This is because of: (1) a lack of therapists who will work with people with I/DD; (2) frequent diagnostic overshadowing by therapists and providers; (3) a lack of knowledge about mental health issues and the stigmas associated with people with I/DD; and (4) logistical problems related to the lifestyles of people with I/DD (in the US), such as a lack of suitable transportation and a lack of privacy in group living situations, which often preclude them from pursuing therapy [83].

Therefore, we define **post-trauma self-regulation (PTSR)** as engaging in one or more *activities* that regulate one's emotions to help cope with the state of *dis-ease* in the moment, outside of (but complementary to) any long-term therapy [55]. Broadly speaking, self-regulation usually requires performing activities that focus one's attention to temper the negative emotions and feelings in a given situation [71]. This paper does not concern itself with the design of specific PTSR activities within an app environment to be used by people with I/DD. Rather, this paper is about the larger design considerations of an app that provides PTSR for people with I/DD. The decision of whether or not to engage in any particular type of PTSR activity is up to the individual with I/DD. Given that people with I/DD are avid users of mobile computing devices [80], apps are one of the easiest ways of providing people with I/DD the ability to perform PTSR.

2 RELATED WORK

In this section, we provide an overview of the work done in research and commercial spaces around mobile-computing-based self-regulation apps. *None of the prior work has focused on the use of technology for PTSR for people with I/DD.* We categorize the extant work on self-regulation into four broad groups, which we describe below.

2.1 Mobile technologies for mental health

Recent years have seen an increasing number of technologically-oriented mental health solutions that have become available. These include: connecting people with help online [16, 45], conversational

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[2]*Triggers* are things like sights, sounds, smells, situations, or depictions that are similar to and in some way evoke a person's traumatic experience and which cause the person to uncontrollably recall and relive the trauma [42].

agents [26, 57, 73], chatbots [30, 62, 78], and virtual reality (VR) systems [27]. Often these health technologies focus on helping people with issues, such as depression and anxiety, by providing treatment and therapies (such as cognitive behavioral therapy (CBT) or exposure therapy) [88]. Such technological approaches to therapy have become necessary due to a lack of easy access to mental health services, stigma, and low mental health literacy in the general population [53] (much like the I/DD community). Consequently, considerable design work is now underway to systematically understand the users of these technologies and build better and more usable mental health technologies [8–10, 22, 41, 45, 76, 88]. These technologies, though important, are different from our work in important ways. (1) The focus of these technologies is often on therapeutic approaches, which are different from, though complementary to self-regulation. (2) These technologies have not been designed for people with I/DD whose lived experiences, motivations, and struggles can be quite different from non-I/DD individuals.

2.2 Research apps for non-trauma self-regulation

Mobile-computing-device-based apps for self-regulation have been investigated in the academic research space as well. These include using a device to record one's emotions, location-tagging them, and sharing them (anonymously, if needed) with others [35]. Other approaches include using slow, repetitive actions to maintain the user's attention [4], providing gentle feedback via soft fascinations[3] [2], and promoting an effortless reflection on any loss of attention [69]. These ideas of repetitive actions and soft fascinations have been extended from monitoring one's thoughts to performing mindful physical activities (e.g., yoga) as well [60]. These apps, not having been designed for someone with I/DD, provide a limited repertoire of often abstract self-regulation activities. Someone with limited working memory (as many people with I/DD have post-trauma) would likely find them difficult to use. Further, if any of the activities/actions/sounds in these apps constitutes a trigger for users who have experienced trauma, the apps do not offer any alternative activities or any form of recourse to deal with the ramifications.

2.3 Commercial apps for non-trauma self-regulation

Numerous mobile-computing-device-based apps are now available that provide a means of self-regulation, primarily through guided meditation practices (e.g., Calm and HeadSpace). We looked at 28 popular self-regulation apps listed on websites like Healthline [33], Positive Psychology [64] and Women's Health Weekly [85]. We provide the list of the 28 apps along with the URL where we found them in the appendix. Usually designed to manage stress, these apps require their users to observe their current state of attention and adjust it, often based on spoken instructions. Most of these apps appear not to be cognizant of the lives of people with I/DD or those who have experienced trauma. These apps tend to blithely offer activities unproblematically, unaware that certain characteristics of the activities and/or the way in which they are presented can

include aspects that trigger trauma survivors. For instance, just the act of asking a trauma survivor to close their eyes for meditation can be triggering and make them feel unsafe and potentially retraumatized [66]. These apps impose a very high cognitive load on the user and require significant working memory, as they often contain an enormous number of self-regulation exercises from which to choose. For instance, the app Insight Timer boasts of having tens of thousands of videos alone, not to mention all of its live content [36]. Moreover, these apps also provide limited instructions and often poor recommendation support. Many of these apps have substantial subscription fees, which can be difficult for many to afford (e.g., Calm [15] and Headspace [32]) [40]. As mentioned above, most of these apps are heavily reliant on some form of meditation practice involving listening to someone guide the activity through spoken cues, which are usually vague and tailored to users who already have experience with meditation and do not require explicit instructions. Not surprisingly, these meditations have been found to be difficult to use for many people who find it hard to keep up with the pace of the instructions [69]. On the whole, these apps constitute part of what is referred to as "self-tracking culture" in [47], which is only fully available to those with sufficient socioeconomic privilege. Thus, those who lack adequate privilege (e.g., older adults, those with less education or lower incomes, people with disabilities and chronic health problems, people living in rural and remote areas, etc.) cannot fully benefit from these technologies and are left behind. In short, whether consciously or not, these apps are designed for highly motivated, non-traumatized, privileged people who have the means to pay for them; they are not intersectionally inclusive.

2.4 Non-commercial trauma-focused self-regulation apps

In recent years, an entire class of free apps has been developed by the US federal government primarily for veterans, members of the military, civilian personnel, and their families to help them cope with the negative effects of trauma. These include apps that: teach mindfulness and meditation practices and routines over time [49], provide a variety of ways to deal with the negative effects of trauma [61, 81], help healthcare providers deal with secondary traumatic stress [67], help families of trauma survivors [24], and help survivors of sexual assault [58, 68]. These apps have many useful features that could be leveraged for people with I/DD (as we shall see from time-to-time in this paper). However, as none of these apps has been designed for people with I/DD, they have several drawbacks in terms of being accessible for our target population. Most of these apps are quite reading-heavy in nature (often necessarily so, as they want their audience to understand trauma, take it seriously, and get help), which can be difficult for people with I/DD, many of whom have limited literacy [34]. Moreover, these apps typically lack effective recommendation services for activities to do, given the often large set of available activities. We believe that these aspects, among others, make these apps not only difficult for people with I/DD to navigate but also difficult for them to operate, especially when used autonomously.

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[3]Soft fascinations are feedback, such as nature sounds, which are meant to be effortless to observe. These are often used in Attention Restoration Theory as a way to recover from mental fatigue [38].

ID	Freq. of interaction w/ people with I/DD	Duration working w/ people with I/DD
P1	2 days/week	4 years
P2	Daily	25 years
P3	Daily	3 years
P4	Weekly	4 years
P5	Weekly	3 months
P6	Daily	5 years
P7	3 days/week	10 years
P8	Daily	17 years

Table 1: Demographic information for the practitioners surveyed in our study. All participants identified as female.

2.5 Trauma-informed computing

In a very recent paper [17], the idea of trauma-informed computing was introduced. The authors, coming from the perspective of intimate partner violence (IPV) and the role of technology is perpetuating it, describe the need for trauma-informed computing via three fictional scenarios they constructed, which reflect their experience working with IPV survivors. The authors then turn to the notion of trauma-informed care, which we explore in more detail below. In basic terms, trauma-informed care asks organizations providing services to trauma survivors to treat these survivors in a way that conveys respect and compassion [21, 31, 46]. This recent paper adapts the notion of trauma-informed care into a broad framework they refer to as trauma-informed computing. The scope of the paper is broad and discusses applying their framework to topics, such as: UX research and design, security and privacy, AI and machine learning, and corporate culture. Therefore the guidelines provided in the paper are designed to be broadly applicable rather than directly relate to the needs of a specific class of technology or to address the needs of a specific community (such as the I/DD community). We similarly apply the notion of trauma-informed care to the development of technology (in the present paper): specifically PTSR apps for people with I/DD. We consider our contemporaneous work as complementary to the one proposed in [17]. We adapt the idea of trauma-informed care specifically to meet the targeted needs of designing PTSR apps for people with I/DD, based on interviews with stakeholders. Consequently, our view of how trauma-informed care maps to technology design differs somewhat from the view presented in [17].

3 INTERVIEW STUDY

Our aim in this paper is to explore the design of **post-trauma self-regulation (PTSR)** apps for people with I/DD that complements therapeutic interventions. In this regard, we wanted to develop a broad understanding of PTSR within the I/DD community. To wit, we interviewed practitioners at an organization in the US that provides trauma services to people with I/DD. As part of their services they help and teach people with I/DD to use self-regulation to cope with their past trauma. Our aim with the interviews was to answer three core research questions. (RQ1) What does post-trauma self-regulation for people with I/DD entail? (RQ2) Do people with I/DD use apps/technologies for post-trauma self-regulation and if so, how? and (RQ3) What should designers be mindful of when they design post-trauma self-regulation apps for someone with I/DD? Below we describe the study methods of our interview.

3.1 Study methods

We interviewed *practitioners* who are affiliated with an adult protective services agency in the US and who help people with I/DD with trauma services. Among the services they provide is helping people with I/DD learn how to engage in PTSR. These practitioners have a global perspective about coping with trauma specifically for the I/DD community. They can therefore provide us with the larger context regarding self-regulation practices within the community. All interviews were conducted over Zoom because of the COVID-19 pandemic. The interview protocol was approved by the institutional review board (IRB), the ethics board, at the University of Rhode Island.

3.1.1 Study design. We conducted semi-structured interviews with participants recruited for our study. We had a script with open-ended questions and interviewees were allowed to wander in their responses. We opened with a brief introduction of our aims followed by questions in four categories: the participant's background, the services their organization provides related to enabling self-regulation for individuals with I/DD, their understanding of the types of PSTR practiced by individuals with I/DD, and their thoughts on ways to more effectively facilitate PSTR among individuals with I/DD. A total of eight (8) practitioners participated in the interviews. All eight interact with people with I/DD on a regular basis and have experience helping them learn and practice self-regulation. The individuals with I/DD with whom our practitioners work have mild to moderate I/DD. Table 1 shows the demographic information for the practitioners.

3.1.2 Study analysis. After the user study, the collected Zoom recordings were transcribed. We applied Braun and Clark's 6-step recursive approach to thematic analysis, as described in [13]. The coding and analysis were completed in a collaborative manner between the two authors, aiming to achieve a richer interpretation of meaning than attempting to achieve consensus would produce. The coding and theme development were done inductively and evolved throughout the analytic process. Table 2 lists the codes that were generated during the thematic analysis. The results of our analysis are summarized in the findings below.

3.1.3 Limitations. The methodology of our study had three main limitations that we briefly discuss. First, all practitioners we interviewed identify as female, though we did not set out to solicit opinions exclusively from female practitioners. We do not believe that this affected the observations in the paper; however, a more

Code Name	Definition
Current self-regulation activities	Self-regulation activities in which individuals with I/DD engage
Potential self-regulation activities	Categories of self-regulation activities that should work for individuals with I/DD
Ersatz apps for self-regulation	Apps that individuals with I/DD turn to for self-regulation (since there is no existing PTSR app for them to use)
Suitability of ersatz apps	Appropriateness of the ersatz self-regulation apps for PTSR for individuals with I/DD
Designing for PTSR	What the PTSR apps for individuals with I/DD should consider in their design

Table 2: The codes used in our thematic analysis of the interviews.

diverse practitioner population could have provided additional perspectives that we might have missed here. Second, all of our participants were from the United States and, therefore, their perspectives and experience may differ from those of practitioners from other regions. Third, we did not talk to individuals with I/DD about how they self regulate on a day-to-day basis. This is because, at this point in our work, the aim was to get a community-level picture of what self-regulation for people with I/DD entails. This is something that we plan to work on in the immediate future.

3.2 Study findings 1: PTSR for people with I/DD should promote empowerment and include diverse activities.

In our interviews, we began by trying to understand what PTSR for people with I/DD entails. We found two main themes in this regard, which we describe next. We provide verbatim quotations, which are edited for brevity and clarity using ellipses and brackets, respectively.

3.2.1 PTSR should enable people with I/DD to gain control over their lives as a way to mitigate some of the effects of their trauma. People with I/DD often lead, as P2 puts it, a highly "managed life." For instance, they live in group homes where they share personal space and resources with others: *"I also think, acknowledging the disability component... that's something that's unique to [people with I/DD]. Like a [person with I/DD] will talk about, in one way or another, how... they might not be able to access certain things because of their disability, like privacy [or lack there of, in their daily lives]." (P3).* Furthermore, the opinions of people with I/DD are often discounted by others: *"... people don't believe people with [I/DD] are reliable narrators of their experiences." (P3).*

Moreover, if people with I/DD are in distress, they are often blamed for displaying such behavior: *"if someone [with I/DD] is distressed, it's like they're doing something wrong or they're having a behavior that's wrong." (P2).* These experiences often mean that they lack power over their words, body, and surroundings, which contributes to their feeling traumatized on a day-to-day basis, which is line with extant literature [52, 86]. Given the pervasive presence of traumatizing events in the lives of people with I/DD the participants felt that one of the main tenets of PTSR should be to allow people with I/DD to regain control over their lives. They brought up three broad ways of empowering individuals with I/DD in this regard:

- Helping people with I/DD to observe and determine their current feelings/emotions in the moment: *"being able to empower them and teach them the skills that they need to be able to [check in and see how they are feeling] in a practical way in their life would be a really amazing goal." (P7).* This is essential because knowing one's feelings or emotions in the

moment is often healing in itself: *"[people with I/DD] enjoy learning [about and] identifying what their feelings are or maybe what they're going through. Even the difficult feelings but they'll come to terms with [them]... in my understanding and observation, it's very healing and it's very empowering." (P8).*

- Enabling people with I/DD to make decisions about their lives, including the type of self-regulation activities that work for them: *"So it's important to make sure that they're taking charge in... any of the decisions being made... allowing people to pick their own [self-regulation activities]." (P6).*

- Providing a means of supporting them as they make these decisions: *"... decrease any barriers or any complexity to them getting whatever support that they might need." (P8).* The idea is to enable people with I/DD to lead a healthy and positive life by taking in account things like *"what are their goals, their dreams, their interests, their preferences, and how can they get those things." (P2).*

3.2.2 Activities used for PTSR should be diverse to give them more choices. Every person has different needs when it comes to self regulating to deal with the negative effects of trauma: *"I think it's good to have choices, like a variation of choices because that's really a big thing too, is that one coping skill might not work for [one] person [while for another person] it might be the best coping skill ever." (P7).* Consequently, when it comes to PTSR, a variety of activities should be offered. Our participants listed a large variety of options that they have seen work for people with I/DD to cope with their trauma. These can be broadly categorized into 6 categories (next to each categorical entry, we list the number of participants who suggested that category): audio-visual activities (e.g., music, video games, and video clips) ($N = 4$), outdoor activities (e.g., gardening/yard work, walks, and traveling) ($N = 4$); establishing social connections ($N = 3$); identifying one's emotions/feelings ($N = 3$); breathing, yoga, and mindfulness practices ($N = 2$); viewing positive affirmations and messages ($N = 2$); and activities that engage a person's creativity (e.g., coloring books and crafts) ($N = 1$). These categories are, of course, not comprehensive but they do give a sense of how diverse PTSR activities can be. Interestingly one participant stated that, for some people with I/DD, activities involving abstract imagery or visualizations can be distressing instead of calming: *"[People with I/DD] feel like [if] it's visually too imaginary [it's] distressing rather than calming. In that same vein, it makes me think that something that can be useful is being a bit more concrete... being less abstract and less imaginary or visual. Like the idea of visualizations is probably not the best route, usually." (P2).*

3.3 Study findings 2: People with I/DD use existing apps for PTSR but these are not well-suited to their needs.

Next, we wanted to understand what apps or technologies people with I/DD use for PTSR purposes. Further, we also wanted to understand how well-suited these solutions were for our population. We describe our findings below. Again, we provide verbatim quotations, which are edited for brevity and clarity using ellipses and brackets, respectively.

3.3.1 People with I/DD use a variety of ersatz apps for PTSR. According to our participants, people with I/DD use a variety of apps for PTSR purposes. These can be grouped into four broad categories (as before, we list the number of participants who suggested each category). They include the use of: audio-visual apps (e.g., YouTube, Netflix, Spotify, video games) ($N = 5$); social media apps (e.g., Instagram, TikTok, Facebook, and Pinterest) ($N = 3$); creativity apps (e.g., coloring books, puzzles, creating music playlists) ($N = 2$); a digital companion (e.g., Care.Coach) ($N = 1$); viewing pictures of cute animals ($N = 1$).

These data show that the apps used by people with I/DD, according to our participants, roughly match the diversity of the PTSR activities that they recommended as potentially useful. The only categories not found here, as compared to the section above, include outdoor activities and observing one's feelings/emotions. It is unsurprising that the former is not included here, since outdoor activities are not suited to implementation on an app modality. It is also unsurprising that the latter is not present here, since all of the apps in this section are essentially ersatz PTSR apps. This means that were not explicitly designed for self-regulation, which often involves reflecting on how one is feeling in the moment. Going forward we refer to the app categories listed in this section as *ersatz apps*. Interestingly, none of our participants mentioned people with I/DD using of any of the trauma-focused self-regulation apps developed for conditions like PTSD (as mentioned in Section 2).

3.3.2 None of the ersatz apps is well-suited for people with I/DD. Although people with I/DD were using a variety of apps for PTSR purposes, they were using apps that were neither explicitly designed for this population nor were they using apps that are designed for coping with trauma. When it came to these ersatz apps, the participants felt that the apps were not well suited for PTSR for people with I/DD. The practitioners explicitly mentioned three categories of ersatz apps when discussing their unsuitability for PTSR for people with I/DD:

- *Commercial non-trauma self-regulation apps:* The practitioners felt that commercial apps were not designed to be usable for people with I/DD because of the cognitive load they impose: *"I would not recommend any of those [commercial self-regulation] apps to any of my clients. I would never. The meditations are weird... You need to know how to do too much independent navigation to use any of those apps. It's too much... There were no pictures on anything... everything should be written at most a fifth-grade reading level. If my client, who's never meditated before, is going to use a guided meditation, like, 'No!' ... I need what's an intro level. I need like a video or something. My clients, they don't use this stuff on a regular basis."* (P3).

- *Non-commercial trauma-focused apps:* The practitioners felt that these apps were not designed to be accessible for people with I/DD, despite being designed for helping with trauma: *"I remember the military app like defining PTSD. That's like a clinical definition of PTSD, right? I don't need that... it's also there's not a lot of personalization, which I think is like the core part of the work we do... I think you just can't personalize any of those apps the way that they need to be personalized for our clients."* (P3).

- *Social media apps:* These apps were viewed as being too risky for being used for PTSR purposes: *"God no! Social media isn't designed for anybody dealing with trauma. No one."* (P4).

3.4 Study findings 3: The design of PTSR apps for people with I/DD needs to promote autonomy, be accessible, and enable social connections

We next asked our participants what designers of PTSR apps should be mindful of when designing for someone with I/DD. The participants' responses can be categorized into three broad categories, which we describe below. Once again, we provide verbatim quotations, which are edited for brevity and clarity using ellipses and brackets, respectively.

3.4.1 Support the autonomy of people with I/DD in design to make decisions about their self-regulation. As mentioned before, one of the most significant sources of trauma in the lives of people with I/DD was not having control over their body, words, and lives in general. Therefore, one of the main design elements that PTSR apps should espouse is the provision of control, that is, helping people with I/DD control the type of self-regulation that they want to do: *"I think people want to have the option of what type of self care that they engage in and what it's relating to... I've noticed having topics people like... food, TV, exercise, and/or trauma and coping."* (P1). In this regard, the app should *not* try to tell people with I/DD what to do. Rather it should guide them to identify what they need: *"I guess listing or being able to identify what it is their needs are, for one, and that's going to vary from individual to individual. So a section... for them to be able to pinpoint or identify, 'okay, I need this' or... 'these are my basic needs'...."* (P8).

Furthermore, supporting autonomy also includes understanding that some (perhaps most) people will not want to talk or engage with the trauma when doing PTSR: *"... framing the app in a way where the individual, if they want to use and talk about their trauma, they can but it's not a requirement to use the app... sometimes somebody might, say, want a self-care activity, might want to do something but doesn't want to specifically think about their sexual assault, doesn't want to specifically think about why they need that self care, just they need a self care activity."* (P6). Moreover, there is a common misconception that PTSR requires engaging with the trauma: *"but we talk about skills... you don't have to talk about trauma to respond to it or heal from it. I think that's a big misconception that people have."* (P3). This notion that PTSR need not involve engaging with the trauma at all builds on our earlier idea from this section where the person with I/DD ultimately gets to decide what works for them when it comes to PTSR.

Finally, supporting the autonomy of a person with I/DD also means being aware that what triggers someone in a given moment is often unpredictable to designers beforehand: *"I think you never know what [someone's trigger] is... because I have a client who was triggered by the word 'guys,' right?... and saying the word 'guys' and being perceived as not feminine was a big trigger for that client and I would mess up. I would have to write myself a note to... remember not to say the word but that's just a small example of what it can look like." (P3).* Since triggers cannot be predicted the design should include appropriate provisions to mitigate the effects of such triggers by: (1) making sure that users do not feel blamed for their triggers: *"You don't want something that would inadvertently make a person feel blamed or shamed." (P2),* and (2) allowing the person using the app to individualize (customize) the app to their personal situation and needs.

3.4.2 Be accessible and intersectionally inclusive in design. In terms of the eventual design of the app, given that it is ultimately being designed for someone with I/DD, it must be accessible to them. Our participants specified several key properties for accessibility. These included: the use of simple and easy-to-understand language that is concrete rather than abstract. The idea is to tend toward over-explaining things within the app: *"I think [the activities] would have to be really broken down. So I know sometimes if I will go on like meditation apps, if I listen to people talk, they sometimes will use very large words, talk about like the space, the heavens. But for some people, that's really not accessible and so just something that's very simple, very clear. If we're breathing in: 'breathe in for three seconds. I'm going to count with you: one, two, three,' things like that. Over-explaining to where you think it's not necessary but for someone with a disability, that could be really helpful because again there's a difference between telling somebody 'breathe in' and 'we're going to breathe in for three seconds through our nose and we're going to try and feel it in our chest or in our stomach.'" (P6).*

An interesting point on this topic raised by one of the participants was that the app should be accessible to people with I/DD without calling obvious attention to that fact. In other words, people with I/DD want to be treated like everyone else, as a person first instead of being approached in terms of their disability: *"an app that's accessible without screaming, 'I'm accessible,'... So not necessarily off the bat, you sign on to the app and it's like, do you need large font?... I just think that puts folks with disabilities off; they've told me it has. So I just think it needs to look like an app that someone without a disability could use but creatively having [the team] who's creating it know that it does need to be accessible and these are some particular things for folks with intellectual and developmental disabilities that you need to know...." (P1).*

The participants also suggested that the design of the material used in the app should be more inclusive, in terms of the types of people shown, than apps have traditionally tended to be. This means reflecting and respecting differences in lived experience in terms of things like language, ethnicity, culture, gender expression, sexuality, religion, and more of the target I/DD community: *"I think inclusion in making sure the app represents folks on a lot of different identities and skin colors. I think also [that] the disability work can be really whitewashed." (P3).* In other words, participants suggested that we take an intersectional approach to the problem of designing

for our target community. When we use the term intersectional approach to design, we mean design that is aware of the multitude of factors that affect the lived experience of a person's life: *"People [with I/DD] haven't just experienced ableism but have also experienced sexism, racism, and homophobia. I think it's important to [consider this intersectionality] for how we [think about] helping somebody." (P2).* Therefore an intersectionally inclusive design of PTSR apps should include content that: accommodates different literacy levels (to promote I/DD accessibility); employs gender-neutral language and avoids both gender binarism and gender stereotypes (to avoid biases like transphobia, homophobia, and sexism); uses images of people with diverse skin tones and body types (to avoid typical content whitewashing and fixations on certain notions of beauty), etc.

3.4.3 Include some form of social connection in the design. An interesting pattern that we observed in the use of the ersatz apps was that people with I/DD were using them to try to engage in social connection in some form or another. This is particularly true for social media apps: *"I know a lot of [people with I/DD]... [use] social media for self [regulation]. A lot of them will do that... for social connection, talking to people, feeling like they're connected, they're not isolated." (P6).* Additionally, the participants also mentioned social connection in the context of using music for PTSR by sharing playlists with others: *"... the person I was talking about who has a communication device... his device connects to YouTube and he shares music videos all the time." (P2).* In the same vein, a recurring theme in the design of PTSR apps was the need to promote social connection for people with I/DD: *"I just envision an app more of like a dialog between people with I/DD as opposed to some of [the] apps that you would see now.... [For PTSR, people with I/DD]... really like... the dialog and the socialization, especially during a time like this. So if they have an app that... really fills the void of the socialization piece that none of [the clients] have right now because they're so isolated. They want to feel like they're talking to somebody and if they feel like they're talking to their peer, that's, to me, even better." (P1).* The participants suggested several alternatives for establishing social connection for people with I/DD as part of PTSR.

- Sending and receiving positive affirmations among people with I/DD as a way to support one another: *"People [with I/DD] really like words of wisdom and hearing things from their peers... I'm wondering if they could have like a daily positive quote from someone who's been through something that they have, that they just check it out because that kind of gets addicting, right? Like I'm waking up this morning, I want to hear what one of my peers has to say about this morning and it's like a positive quote to get their day going. I think things like that would be cool just coming from their peer or if you wake up having a crappy day, 'here's what I've done. If you click on this, you can do it for yourself too.'" (P1).*
- Utilizing voice-based interactive systems that help the person feel connected (even if that's not with another person but rather with a bot): *"If there's voice activation, you don't want something that's bossing you around... You want something that makes you feel positive about yourself and also helps you feel like you're in control." (P2).*

- The words and lived experience of people with I/DD should be conveyed as part of the interaction: *"If [people with I/DD's] words and experiences are somehow captured in the app, I just think that's a catch... I think the folks are more inclined to tune in when it's... coming from somebody that's lived the experience and has a suggestion that worked for them."* (P1).

4 TRAUMA-INFORMED CARE (TIC)

Based on the findings of our interview study, we posit that one way of approaching the design of PTSR for people with I/DD is based on the notion of *trauma-informed care* (TIC). TIC is an idea obtained from social work practice that is used by organizations to support traumatized individuals. Before we delve into how this can be done (in the next section), in this section we provide a brief overview of TIC, its suitability for helping trauma survivors with I/DD, and its five main criteria.

4.1 Overview of trauma-informed care

The main idea behind TIC is that organizations providing trauma services should consider the roles of trauma and its lingering effects on the lives of individuals who have experienced trauma. Hence, the idea is for the entire culture of an organization that deals with trauma survivors to be aware of the trauma their clients have experienced [21, 46]. Organizations providing TIC services rely on their staff's knowledge about trauma in responding to clients in ways that convey respect and compassion, foster the autonomy of the survivor, and aid in building coping strategies [21, 46]. TIC is different from trauma-focused therapy (e.g., exposure therapy), as its primary goal is not to directly address or process the past trauma (i.e., the root of the problem *per se*) but to provide a process to deal with what the client presents as a result of their traumatic experience(s) [46].

In recent years, there has been an increased understanding of the need for TIC for people with I/DD. Given that people with I/DD often need organizational support to manage their daily lives and require such support throughout their lives, TIC has been seen as a natural way of helping people with I/DD manage their situation [39]. It has been recognized that, through TIC practice, people with I/DD can: develop a sense of safety; feel reduced shame and guilt; and be empowered and engaged to minimize the impact of the traumatic experience [21].

4.2 Trauma-informed care and the postmodern model of disability

Even though TIC did not necessarily develop in the context of helping people with disabilities, it aligns with the *postmodern model of disability* as described in [48].

4.2.1 Models of disability. Mankoff et. al provided a beautiful overview models of disability in this seminal paper [48]. In it they described three models of disability, which we quickly summarize here for context. Traditionally, disability has been conceptualized first as something to cure, as part of what is known as the *medical model* of disabilities. This model conceives of people with disabilities as *lacking and in need of being "fixed" to bring them to some notion of "normal"*. However the medical model rests uncomfortably

on an assumption that the goal is normality - that is, the elimination of disability. Conceptualizing disability using the medical model can have drastic negative consequences on the autonomy and decision-making power of people with disabilities [48]. This was followed in the 1970s by the *social model*, which shifts the narrative from a need for cure to a need for care where *patients*, not clinicians, become the leaders in managing their conditions. The social model and the associated independent living movement promote self-advocacy and peer support as the first steps toward full participation in society, citizenship, and leadership development. The social model, however, also has some limitations. For example, if disability is only defined at the level of society, then the individual's experience is to some extent invalidated and the question of accommodations at the level of the individual sidelined [48]. Among the models that have been proposed to move beyond the medical and social models, the *postmodern model* is, to us, most apt. Based on the concept of postmodernity from the humanities, this model incorporates some aspects of the medical and social models that can still be considered relevant. Rather than simply claiming that these former approaches no longer have anything to offer: it includes a focus on the individual's experience of disability (similar to the medical model, though significantly expanded) as well as a consideration of how society constructs disability (from the social model). The postmodern model privileges each individual's unique lived experience, complete with the complexity and nuance of everyday life [48].

4.2.2 Trauma-informed care and the postmodern model of disability. Trauma-informed care embodies the postmodern model of disability for many reasons. First, TIC does not view trauma purely as a medical issue to be cured. It achieves this by viewing negative effects of trauma as coping mechanisms for the trauma survivor as opposed to seeing them as some form of pathology, thus highlighting the survivor's resilience. This reframing of negative trauma effects as adaptations ultimately allows support organizations to help the survivor develop healthier coping mechanisms without stigma or guilt [39]. Second, TIC considers traumatic experiences (e.g., a feeling of loss of bodily autonomy) not as past events but as defining experiences that shape the core of the survivor's current identity. Therefore, TIC fosters the survivor's autonomy, control, and say over their own well-being [39]. Third, TIC is careful not to ascribe the cause of negative trauma effects to existing disabilities. Consequently, organizations implementing TIC take extreme care not to use language, behaviors, scenarios, or practices that can potentially retraumatize a trauma survivor [39]. Overall, TIC, being cognizant of the negative effects of trauma on the lives of people, is by its very nature an ideal framework to meet the needs of people with I/DD affected by trauma.

4.3 The five criteria of trauma-informed care

The 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 [31]. These criteria were originally defined for the general population of trauma survivors. However, in recent years these criteria have been seen as applicable to the I/DD community as well [39, 86]. Based on the work by John Keesler

[39], in this section we define the five criteria of TIC in terms of people with I/DD:

Safety: The organization should recognize that people with I/DD are likely to have a history that includes trauma. Consequently, it should explicitly provide an environment where the person with I/DD feels both physically and emotionally safe. Another way of putting it is that the environment should be such that it does not retraumatize the person with I/DD.

Trust: Trust is essential to the care process to ensure that the person with I/DD is able to develop the autonomy, initiative, and competence required to empower themselves to manage with the effects of their trauma. From an organizational standpoint, this criterion relates to a clarity of expectations for the person with I/DD in terms of receiving consistent service delivery across the organization.

Choice: Oftentimes trauma causes a person with I/DD to lose their sense of control over their lives and their bodies. The concept of choice within TIC is an attempt to enable the person with I/DD to make their own decisions and gain a sense of control over their recovery and life.

Collaboration: When a person with I/DD receives services for their trauma from a support organization, a power differential can exist in that relationship. If not carefully equalized, such a power imbalance (often subtle and insidious) can increase feelings of vulnerability in the trauma survivor. An essential feature of TIC is equalizing the potential power differential between the survivor and any support organization (and their staff) in decision-making around care. For instance, people with I/DD are often prone to the seek acceptance of others and are particularly vulnerable to instinctive compliance to authority. Therefore, the collaboration criterion requires that we remind trauma survivors with I/DD that they have the right to ask questions, decline services, and make requests.

Empowerment: This criterion essentially does two things. First, it recognizes the behavior of a trauma survivor with I/DD as a legitimate way for them to deal with past trauma. It therefore validates their current experience, thus empowering trauma survivors to take their well-being in their own hands. Second, it recognizes the individual strengths, skills, and abilities of the person with I/DD and aids them every step of the way. This focus on the survivor's existing strengths and skills is seen as an integral way to help them realize that they may already possess the resources necessary to develop a solution for any obstacles they face in dealing with the effects of the trauma.

5 INCORPORATING TRAUMA-INFORMED CARE INTO THE DESIGN OF PTSR APPS FOR PEOPLE WITH I/DD

In this section, we explore the design space for PTSR apps for people with I/DD using the notion of trauma-informed care (TIC) discussed in Section 4. To the best of our knowledge no prior work has attempted to look at applying TIC to app design. In the rest of this section we discuss how each of the TIC criteria can be adapted to the design of PTSR apps by exploring important design guidelines related to each criterion. We derived these design guidelines from the responses from the interviews we conducted as well as our years

of experience designing technologies for people with I/DD. Next we describe each of these design guidelines, which are summarize in Table 3. In this section, we use the term *user(s)* to specifically mean *individual(s) with I/DD.*

5.1 Designing for safety

The first criterion we consider is that of safety, where the idea is to provide users with a sense of physical and emotional safety. Likewise we define safety within PTSR apps as designing with the intent to minimize any retraumatization of users and to provide a means for them to cope with negative trauma effects. We suggest three guidelines for ensuring the safety criterion for PTSR apps.

Mitigate known negative trauma effects. The design of PTSR apps should be cognizant of the *dis-ease* that its users may be experiencing and ensure that it does not exacerbate it. Consequently, when designing PTSR apps, similar efforts must be made to help users to manage known negative trauma effects. For instance, the app should be cognizant of the fact that, for some people with I/DD, self-regulation activities that are abstract and involve the imagination, like visualization activities, can be distressing rather than calming. Similarly, closing one's eyes and going right into a meditation with no preparatory safety measures is not ideal for those who have experienced trauma (including people with I/DD). Thus, the app should give users options of various safety measures they can take before and/or during meditation (like keeping their eyes open or first check that the doors are locked) to make sure they feel safe and in control in their surroundings.

Be actively supportive of the lived experience of people with I/DD. The I/DD community is diverse. Thus the design of PTSR apps should be considerate of the differences in lived experience in terms of things like language, ethnicity, culture, gender expression, sexuality, religion, and more of the target I/DD community. An app that does not actively represent a worldview that is supportive of the diversity of people with I/DD essentially rejects non-normative body and mental states, which is oppressive and traumatizing, thus negatively impacting user safety [59]. For instance, any voice communication in PTSR apps designed to be inclusive of trans and nonbinary people with I/DD should include more than just stereotypically cis male and female genders in its vocal elements.

Assume that "potentially anything can trigger": For someone who has experienced trauma, anything that reminds them of their traumatic experience can trigger negative effects. Therefore, designers need to be aware of the fact that even self-regulation activities can potentially trigger users. Triggers are inherently personal and are not the same for any two people [42]. It is thus often very difficult for designers to know *a priori* what can trigger a user when using PTSR apps. We thus believe that PTSR apps should be designed with the "potentially anything can trigger" mindset, which means that it should: (1) use non-judgmental language and features in the app and (2) include a variety of self-regulation activities from which to choose, including offline activities that people with I/DD like (some examples that participants in our study mentioned include: sit with a pet, gardening, coloring, taking a walk, mowing the lawn, being outdoors, yard work, and crafting).

TIC criterion	Guidelines
Safety	1. Mitigate known negative trauma effects
	2. Be actively supportive of the lived experience of people with I/DD
	3. Assume that potentially anything can trigger
Trust	4. Ensure authentication to protect access to user-generated personal data within the app
	5. Never take away recognition for prior successes
Choice	6. Provide a diversity of choices by designing for a variety of abilities
	7. Guide users through the choice-making process
	8. Give users an easy-to-understand way to express their current feelings/emotions
Collaboration	9. Provide the ability to interact with others
	10. Provide tools that converse directly with users
Empowerment	11. Provide accessible information on trauma
	12. Provide customized, pithy messages of support

Table 3: A summary of guidelines obtained for incorporating trauma-informed care into the design of PTSR apps

5.2 Designing for trust

The second criterion is to develop trust with people with I/DD. When it comes to PTSR apps, we define trust as an app's ability to foster confidence in users, such that they keep using the app to the fullest extent. We suggest two guidelines for ensuring the trust criterion for PTSR apps.

Ensure authentication to protect access to user-generated personal data within the app. PTSR apps provides services and features that are intensely personal and should not be available for anyone else to see without explicit permission from the user. For instance, one could imagine an app that allows a user to journal or check in about their emotions and feelings at different points in time. For a user to be able to avail themselves of the benefits of journaling/check-ins, they have to feel safe in doing so honestly. Providing a way to secure this within an app from any unauthorized access is a powerful way to incentivize users to engage with such features. In this regard, one of the main features an app should have is authentication, especially for any personal data. Authentication would ensure that only the user can access their personal information. Indeed, password-based authentication is used by the Safe Helpline app [68] to control access to any user-generated information. However, it frequently requires one's password to be retyped (approximately once every five minutes), which can make using the app tedious and, for people with I/DD, it can make using the app difficult. Designing an authentication solution that works for people with I/DD in the context of protecting the content of PTSR apps is a challenging problem, given that people in this population often need to share their passwords with close family members [80].

Never take away recognition for prior successes. Having incentives within the app is a powerful way to encourage users to use PTSR apps over time. The idea of giving people incentives for using the app came up during the interviews: *"So maybe having some sort of incentive or like... "Oh, you completed this series of coping skills, you get a badge"... because I also have a background in applied behavior analysis, so I think creating incentive to show that they accomplished something, it would be helpful for them to wanting to be engaged in it." (P7).* Often incentives within apps (in general) are designed to be negative in nature, where prior rewards are rescinded if certain goals are not met. This can be clearly seen in apps where an anthropomorphic virtual being becomes happier and sadder with app use and disuse, respectively [18, 29, 63]. However, in our prior work we found that incentives designed for people with

I/DD should never penalize and should only add to prior successes [34]. Consequently, any incentive elements in PTSR apps should therefore accumulate in-app successes. We believe that this would allow users to trust the motives of PTSR apps (e.g., that the app is not negatively judging the users' performance) and therefore use it more fully.

5.3 Designing for choice

The third criterion is that of choice, where people with I/DD are given the chance to make choices and gain control over their recovery and life. PTSR apps that incorporates the choice criterion should provide their users with a variety of ways to achieve their self-regulation goals. We suggest three guidelines for ensuring the choice criterion for PTSR apps.

Provide a diversity of choices by designing for a variety of abilities. One way to increase the choices for users of PTSR apps is to ensure that a given self-regulation activity is available at different levels of difficulty to accommodate the different cognitive abilities of people with I/DD. For instance, a jigsaw puzzle activity designed for PTSR could provide several different versions of the same puzzle with differing degrees of difficulty. For instance, in addition to allowing users to use hints or not, this activity could also offer things like different numbers of pieces or different degrees of intricacy in the image. Offering several difficulty levels for an activity would allow users to select a level not only based on their general abilities but also according to what they feel capable of doing on a given day or in a given situation.

Guide users through the choice-making process. So far we have argued for the need for a diversity of choices for self-regulation activities. However, as the number of self-regulation activities within an app increases, it is not enough for an app simply to provide a list of all of the options. PTSR apps should include a recommender system to offer users self-regulation activity suggestions in order to help facilitate the task of selecting an activity and thus reduce the cognitive load imposed on users. However, given the negative effects of trauma on individuals with I/DD (as described in Section 1.1), such as impaired working memory and a tendency to be easily distracted, the recommender system may have to considerably limit the number of options shown at a time. That being said, any PTSR app's recommender system should be careful just to suggest options and not dictate what the user should do.

Give users an easy-to-understand way to express their current feelings/emotions. How to design a recommender system in PTSR apps for people with I/DD is an open question. One crucial input for the recommender system is the current emotional state of the user, which is something that extant trauma-focused self-regulation apps often offer. For instance, PTSD Coach [66] provides a barometer from 1 to 10 that can be used to indicate one's level of *distress*[4]. This is a good approach for populations without I/DD but it involves an abstract way of expressing how one is feeling in the moment, which can be difficult for people with I/DD to determine about themselves [74]. Consequently, an app designed for people with I/DD needs to: (1) explicitly guide the user through the process of determining how they are feeling in that moment, perhaps through an illustrated, guided emotional check-in process [37] and (2) make the manner of expressing the user's level of distress less abstract, such as through the use of a scale with faces to represent the different emotions, as in [65].

5.4 Designing for collaboration

Traditionally, the collaboration criterion is about equalizing the power differential between the individual with I/DD and the staff at a support organization. When it comes to PTSR apps, it is clear that collaboration needs to be defined differently. Given the nature of mobile computing devices, in that they are typically devices for individual use, working with mobile apps is usually a solitary activity. Furthermore, self-regulation, which is the focus of this paper, can increase the user's sense of isolation even more. As P6 pointed out (in Section 3.4.3), one of the biggest sources of difficulty comes from being isolated from others. Therefore, PTSR apps, as part of the collaboration criterion, should actively allow the user to communicate with others in a meaningful fashion and to engage in collaborative activities and community formation [6]. We suggest two guidelines as part of the collaboration criterion for PTSR apps.

Provide the ability to interact with others. We believe that PTSR apps for our population should provide a means for users to interact with others for social support. This can be friends and family, allies, a designated trusted person, therapy or support groups, and other people with I/DD. This support can take many forms, including informational support, emotional support, personal network support, self-esteem support, and even tangible in-person support [19]. For instance, several trauma-focused self-regulation apps, such as those designed by for US Department of Defense personnel [61, 68], provide their users with a means to call someone to talk. However, these apps primarily focus on phone-call-based communication. One way of promoting the ability to communicate with others for people with I/DD is to leverage the paradigm of social VR. Social VR would allow individuals with I/DD, who otherwise live highly managed lives, to move around and communicate with others in a simulated, immersive space in imaginative ways. VR would thus allow them not only to perform PTSR but also to interact with others on their own terms: the virtual environment would allow them to socialize without having to wait for care assistants to arrange transportation, etc., as they often do when physically socializing

with others. Giving this community unmediated access to socializing would reduce some of the very sources of repeated trauma that they endure.

Provide tools that converse directly with users. PTSR apps need not only promote social collaboration involving other individuals. One can also imagine PTSR apps interacting directly with users to simulate social interactions, similar to AI-assisted chatbots or digital voice assistants. Such interactive tools can help people with I/DD feel less isolated in the absence of others with whom to interact. However, for interactive tools to be truly beneficial to individuals with I/DD, they should react and talk like a peer (i.e., another person with I/DD). At a minimum, existing chatbots and voice assistants have to become more inclusive and be trained on data emanating from people with I/DD.

5.5 Designing for empowerment

In an organizational context the empowerment criterion is about validating the individual's trauma experience and focusing on their abilities[5]. In terms of PTSR app design, we leverage the notion of knowledge is power and define empowerment as accessibly providing the user with information about trauma, its manifestations and effects, and different ways to cope and heal. The availability of information surrounding trauma is a powerful way to validate users' experiences, remove any stigma surrounding trauma [28], and better foster their ability to engage in self-regulation. We suggest two guidelines for ensuring the empowerment criterion for PTSR apps.

Provide accessible information on trauma. Apps focused on trauma for people *without* I/DD often provide a lot of information (in the form of reading material) about trauma and why it is important to address it [61, 68]. Many non-trauma commercial self-regulation apps similarly provide a lot of information about the importance and benefits of meditation practices [75, 82]. However, such a reading-intensive approach is not appropriate for an I/DD population. Prior work in HCI/accessibility has identified several approaches for teaching, informing, and skill-building for the I/DD community. Some of the major findings include recommendations to: (1) use images [11, 54], interactive content, and videos [5, 23]; (2) use concrete, large, differentiated icons and symbols [7]; (3) make the content accessible by supporting audio descriptions of images [3, 79] and accommodating different levels of literacy [20]; (4) reduce information overload [20]; (5) use positive reinforcement for successful engagement with the content [11, 43]; and (6) provide self-paced learning capabilities [43, 44, 54, 70]. These approaches should be adapted to convey information about trauma and self-regulation to people with I/DD within PTSR apps.

Provide customized, pithy messages of support. Another way to empower users via PTSR apps is to provide short affirmations that validate their current experience and reduce any stigma surrounding trauma. Once again these messages have to be designed with the capabilities of users in mind. For instance, in our prior work [34], we developed an abuse-recognition tool for people with I/DD

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[4]PTSD Coach uses the catchall term distress to signify one or more of a host of psychological and physiological states ("anger, sadness, fear, pain, stress, worry, or anything negative they are feeling").

[5]The empowerment criterion in this context lends itself naturally to the notion of ability-based design in HCI [87]. We believe that an entire app, in order to be accessible to people with I/DD, has to be designed with empowerment in mind. Therefore, we do not list ability-based design as a specific guideline in this section, as we view it as a meta-guideline that holds for any app designed for people with I/DD.

that frequently reminds users that "abuse is not their fault." It is understood that people with I/DD often need repetition to fully appreciate a concept [34]. Consequently, such empowering, easy-to-understand messages should appear *passim* throughout an app and should be repeated often. Moreover, for such messages to be effective for a variety of people with I/DD, the messages should be presented via multiple modalities (such as text, pictures/symbols, audio, and video) and should be in the voices of people with I/DD.

6 CONCLUSION

People with I/DD are some of the most traumatized individuals in the US. We posit that mobile-computing-based apps have the potential to help people with I/DD deal with the negative effects of trauma. In recent years a plethora of research, commercial, and non-commercial self-regulation apps have become available but they have not been designed for people with I/DD. Thus this community has turned to cobbling together aspects of ersatz apps for self-regulation. However, the apps this population has been using were never designed for them, nor are they appropriate for coping with trauma. Consequently, we interviewed eight (8) practitioners at a trauma services organization in the US to better understand what it would take to develop post-trauma self-regulation apps for people with I/DD. Based on the interview responses, we then developed a set of guidelines, based on the social work practice of trauma-informed care, to design post-trauma self-regulation apps for people with I/DD. In the future, we plan to instantiate a prototype of a PTSR app based on our design guidelines and then assess the app through user studies involving members of the I/DD community.

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APPENDIX

The following are the 28 commercial apps that we looked at in 2021 as part of this work. Most of these apps are paid (21) or freemium (5). The names of the apps and the URLs where we obtained them are as follows: **Calm** (https://www.calm.com), **Breethe** (https://breethe.com), **Headspace** (https://www.headspace.com), **My Life** (https://my.life), **Buddhify** (https://buddhify.com), **Inspace** (https://inscape.life), **Breathe+** (https://dynamicappdesign.com/#Breathe), **Oak** (https://www.oakmeditation.com), **Whil** (https://www.whil.com), **Simple Habit** (https://www.simplehabit.com), **Petit Bambou** (https://www.petitbambou.com/en/), **Waking up** (https://wakingup.com), **Prana Breath** (https://pranabreath.info), **The Mindfulness App** (https://themindfulnessapp.com), **Sattva** (https://www.sattva.life), **Insight Timer** (https://insighttimer.com), **Meditation Studio** (https://meditationstudioapp.com), **Let's Meditate** (https://play.google.com/store/apps/details?id=com.meditation.elevenminute), **Happy Not Perfect** (https://happynotperfect.com/), **Omvana** (https://www.omvana.com/), **Welzen** (https://welzen.app/), **Relaxing Melodies** (https://www.relaxmelodies.com/), **10% Happier** (https://www.tenpercent.com/), **Simply Being** (https://apps.apple.com/us/app/simply-being-guided-meditation/id347418999), **Aura** (https://www.aurahealth.io), **Unplug** (https://www.unplug.com), **Enso** (https://www.ensomeditationtimer.com), and **Meditation Nest** (https://appadvice.com/app/meditation-nest/1460053458).