



Leveraging technology for post-abuse peer support for people with intellectual and developmental disabilities

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ABSTRACT

Our aim in this paper is to leverage technology to facilitate peer support for abuse survivors with intellectual and developmental disabilities (I/DD). In this regard, we talked to staff from a trauma services agency in the US that has experience providing post-abuse peer-support work. We found that: originally peer support sessions were exclusively in-person sessions that enabled the establishment of a productive connection and building trust between the survivor and the peer leader. However, since COVID-19, peer support sessions has also been provided online via teleconferencing and structured presentations. These online sessions have the advantage that they make it easier for survivors to participate in peer support. However, they often end up diminishing the peer-survivor connection that in-person sessions enabled. Based on these findings, we suggest design of technologies that can enable online peer support to establish a productive connection between survivors and peers as in-person sessions do.

CCS CONCEPTS

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

KEYWORDS

peer-support, intellectual disability, developmental disability, trauma, design

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1 INTRODUCTION

In the US, the rate of violent crime (rape or sexual assault, robbery, and aggravated assault) against people with disabilities is more than three times the rate for people without disabilities [11]. The

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situation is particularly dire for adults with intellectual and developmental disabilities (I/DD)¹, who experience some of the highest rates of crime and assault [15].

Once the abuse of a person with I/DD is reported to the authorities, social service agencies (state agencies in the US) often take action and provide a variety of social and trauma services and support for the survivors, such as medical help, legal help, counseling, and financial assistance [4]. One such service that has recently been developed and offered to abuse survivors with I/DD is *peer support*. **Peer support** is the notion of leveraging social relationships in the treatment of disease and the maintenance of health and well-being [8]. Peer support is known to have the potential to address specific issues for people with disabilities, including barriers to treatment, stigma, and the need for accommodations that are not always recognized by other service providers and programs [22]. The main *aim of peer support*, in this context, is to allow a survivor of abuse with I/DD to *establish a productive connection* (i.e., interact with, connect to, and learn from) someone who has gone through something similar - a **peer** - who is trained to listen, inspire, empower, and help actively cope with the aftereffects of abuse. Peer support is often beneficial to the peer as well as the survivor [30].

However, there are often systemic and personal barriers that prevent or impede people with I/DD from accessing peer support post abuse [33]. These include: (1) a *limited number of organizations providing post-abuse peer support* for survivors with I/DD and (2) *logistic difficulties* related to the lifestyles of people with I/DD, who often live highly managed lives that can preclude them from pursuing peer support [33].

Our aim in this paper is see how to leverage technology to facilitate the peer support process, given these barriers. In order to explore whether and how technology could benefit peer support for survivors with I/DD, we first need to understand two things: **(RQ1)** How are post-abuse peer support sessions structured for people with I/DD and why? and **(RQ2)** How is technology currently used in the provision of such peer support sessions, if at all? To answer these questions, we conducted 11 semi-structured interviews with staff from an organization in the US that provides trauma support, who have experience providing post-abuse peer support for survivors with I/DD. Specifically, we spoke with eight neurotypical **staff members**, who help facilitate the peer support and trauma services, and three **peers**, who are individuals with I/DD who lead the peer support sessions.

¹Based 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 lifelong [1]. In the US, there are over 7 million people with intellectual and developmental disabilities (I/DD) [21]

We found that, prior to the COVID-19 pandemic, peer support sessions were exclusively conducted in-person and were designed to foster the sharing of experiences and trust-building between the **client** (i.e., the survivor with I/DD) and the peer. Then and now, the individual needs of the client determine the focus of the session and the peers play a primary role in creating the *session activities* for the client. Since COVID-19, peer support sessions started to leverage technology in new ways. In addition to in-person sessions, peer support was now mediated via teleconferencing tools and structured PowerPoint slides. These online sessions have the advantage of making it easier for clients to participate in peer support and allowing peers to conduct more sessions. However the online version of peer support often ends up diminishing the most beneficial aspect of peer support - the establishment of a productive connection between the peer and the client - given the new lack of immediacy and by changing the nature of the interaction from interactive to more unidirectional (peer-to-client). Based on these findings, we recommend the design ideas for technologies to help make peer support more readily and widely available, provided that it be designed in a way that attempts to bring it more in line with establishing a productive connection between the peer and the client.

2 RELATED WORK

In this section, we provide an overview of the work done in the context of providing technology-mediated peer support. We categorize the extant work into three broad groups, which we describe below.

2.1 Efficacy of peer support in various contexts

The last few years have seen numerous studies on evaluating the efficacy of technology-mediated peer support for a variety of populations, including: college students learning to code [10], providing emotional support to graduate students pursuing advanced degrees [14]; home care workers, in the context of performing emotional labor [25, 26]; gig workers building connections and organizing collective action [34]; understanding the human and logistic infrastructure needed for facilitating mental health peer support [9]; hospital patients helping each other better understand the hospital system and talking to the providers [12]; immigrants forming peer networks to better their language skills [20]; informal online support for people who engage in self-injury [17]; people with substance-use disorders [19, 27, 28]; support for parents of disabled children [3]; and helping veterans going through a mental health crisis [13]. This prior work demonstrates the efficacy of peer support as a process that assists a variety of individuals in many different contexts. However, thus far, none of these efforts has looked at peer support in the context of individuals with I/DD conducting such sessions, who need help with planning their sessions, putting their ideas into action, accommodating people with a wide range of abilities (including people who are non-verbal), and help with on-the-spot self regulation in the event of triggering conversations.

2.2 Technologies for peer support

In addition to understanding how peer support works and helps in various contexts, work has also been done to develop technologies

that facilitate peer support. These include: understanding what design features users of technologies for peer support for people with mental illness would like to have [23]; designing chat systems for promoting talk therapy as part of mental health peer support [24]; a chatbot for sharing and support during the COVID-19 pandemic [7]; and designing social-media-based peer support for various contexts, such as weight loss [18] and HIV management [16]. None of these technologies has been designed from the standpoint of someone with I/DD. Therefore they neither take into account the abilities and needs of someone with I/DD nor do they consider peer support in the context of abuse.

2.3 Impact of peer support in the context of people with disabilities

Very little work has been done in the context of peer support for people with disabilities. What has been done includes efforts to demonstrate the importance of one's peer also having the lived experience of a disability (including some I/DD) when helping others with disabilities through peer support [31]. Further work has focused on understanding the help that peer support provides people with disabilities who have substance use disorders [22]. This work, however, primarily focused on other kinds of disability. Overall, the paper found that people with disabilities (which again only included a few individuals with I/DD) who also have who have a substance use disorder benefit from peer support. However, improved approaches were needed to ensure that disabled people could overcome the barriers to getting peer services and staying engaged with them [22]. Finally, specifically in the context of I/DD, work has been done to understand providing peer support among other types of professional support, to parents with I/DD who have experienced domestic abuse [6]. This study found that parents with I/DD benefited from peer support, provided it was structured and delivered with respect. Even though all these studies involved with people with I/DD, our work is different in scope in several ways: (1) our work is exclusively focused on individuals with I/DD in the post-abuse context, (2) we exclusively focus on peer support and not its intersection with other related social services, and (3) we look at the issue of designing technology-mediated post-abuse peer support for individuals with I/DD, which has thus far not been examined in the literature.

3 INTERVIEW STUDY

Our aim in this paper is to see how technology can be leveraged to facilitate the peer support process as one means to attempt to counteract the effects of the barriers to peer support. In order to do so, we first needed to better understand peer support in the post-abuse context for adults with I/DD. In this regard, we interviewed two groups from an organization in the US that provides trauma services, including peer support, to people with I/DD: (1) *staff members*: individuals who help facilitate the peer support and other trauma services and (2) *peers*: individuals with I/DD who conduct the peer support sessions. One of the services that these two groups work together to provide is peer support for other adults with I/DD who have experienced abuse.

3.1 Study goals

We sought to answer two research questions with the interviews. **(RQ1)** How are post-abuse peer support sessions structured for people with I/DD and why? and **(RQ2)** How is technology used in the provision of such peer support sessions, if at all? The interview protocol was approved by the institutional review board (IRB), the ethics board, at our institution.

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 the interviewees were permitted to wander in their responses. We opened with a brief introduction of our aims, then asked questions about how they would describe the following: the services their organization provides for individuals with I/DD, how the in-person peer-support sessions work, the role of peers and staff members in the peer support process, and the role of technology in the provision of peer support. We interviewed a total of *eight* staff members. These staff members were of two types: navigators (N=5) and peer support specialists (N=3). Though these groups have different roles, in terms of peer support, both essentially facilitate and support the peer support sessions. We refer to the staff members using the IDs P1 to P8. The staff members with whom we spoke have been working with people with I/DD anywhere from 3 months to 25 years (mean experience, 8 years). In addition we interviewed *three* peers who are individuals with I/DD and who conduct the peer support sessions. We refer to the peers using the IDs L1 to L3. All 11 participants with whom we interacted have experience providing post-abuse peer support for individuals with I/DD. The clients with whom our staff members work have mild to moderate I/DD. All interviews were conducted via Zoom.

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 [5]. The coding and analysis were completed in a collaborative manner between the two authors. The coding and theme development were done inductively and evolved throughout the analytic process. Table 1 lists the codes that were generated and the results of our analysis are summarized in the findings below.

3.1.3 Limitations. The methodology of our study had two main limitations that we briefly discuss. First, we only spoke with individuals who worked in one trauma services organization. We do not believe that this had a major effect on the observations in the paper; however, a more diverse participant population could have provided additional perspectives that we may have missed here. Second, all of our participants were from the United States. Thus their perspectives and experiences may differ from those of peer support providers from other regions and cultures. Finally, for this work, we did not talk to individuals with I/DD (clients) about their experience with peer support. This is something that we plan to work on in the future.

3.2 Findings 1: In-person peer support sessions are: structured around the client's needs, led by peers, and organized by staff members

The original peer support sessions, around which the program was designed, were exclusively in-person sessions. Therefore, in our interviews, we began by trying to understand how in-person peer support process worked and what they sought to achieve. We found five main themes in this regard, which we describe below. We mark edits for brevity and clarity with ellipses and brackets, respectively. Quotes from the peers are written in the first person.

3.2.1 Peer support sessions typically have four participants. Even though the peer support sessions essentially center on the connection between the client and peer, the session itself is an interdependent ecosystem of four individuals: the navigator, peer support specialist, peer, and the client. The navigator's role is to facilitate the session: *"The navigator's role is really like the facilitator."* (P3). A peer support specialist is present in the in-person sessions to support the peer (and sometimes the client): *"mainly [the peer support specialists'] primary support is for the peers but when [they] run peer meeting sessions, [the peer support specialists] are working directly with the clients who are coming in."* (P7). The peer leads the session with the client: *"The idea is that the peer recognizes and can relate and sort of offer their support [to the client]."* (P1). As a result of the limited number of peers in the program, these sessions are available only about once a month for the clients: *"So we meet about once a month with each person"* (P2).

3.2.2 The client's needs decide the focus of the peer support sessions. The individual peer support session centers around the needs of the client: *"That's kind of the cool thing about the peer support meetings is that it's really... it runs based off of what that client what wants to talk about."* (P1). Clients who agree to participate in the peer support process inform the navigators about what they want to get out of the process: *"[The navigators] talk to [the clients]. We ask them their interests, different things dealing with trauma, various experiences if they want support with."* (P7). Further, the navigators, along with peer support specialists, help the peers to practice for each upcoming customized session, as needed, and how to work with different kinds of clients: *"Practicing specifically... on how to build rapport... what to do with a really talkative client, what to do with a client who doesn't say anything, you know, all of those things to try to prep them to be ready."* (P3).

3.2.3 Peers are central to deciding which activities to offer in a session. Once the information about the client's needs are conveyed by the navigator to the peer, it is the peer who then takes the lead in determining which **activities** will be offered in the session: *"It's all [the peers]. [The navigators] have nothing to do with the creation [of the meeting activities].... The only thing [the navigator does] is presenting what the [client's] hobbies are, what their interests are, and then [the peers] go forward with that."* (P3). Individual peers sometimes have their niches, when it comes to creating activities: *"[Peers] have things planned or they kind of have a special focus. For example, [one peer] really enjoys creating social stories... If [they] are working with someone, they may offer such activities [based on the client's needs]."* (P7).

Code Name	Definition
Session attendees	Who is present during peer support and what kind of role do they play in the process?
Session activities	What happens during a typical in-person peer support session?
Activity design	What activities are used in a session and who creates them?
Peers' experience	How do peers view their role?
Online sessions	What happens during a typical online peer support session?

Table 1: The codes used in our thematic analysis of the interviews.

3.2.4 Peer support sessions accommodate diverse activities. One of the biggest elements of in-person peer support is establishing **trust** between the peer and client, which is essential for establishing a productive connection between them: *"I want them to trust me. If they don't trust me, I can't work with peers. So I get to know them, and they might tell you what happened to them, and [the clients] want open conversation."* (L2). Consequently, every session is customized, involves offering the client a variety of activities from which to choose, and going over the agenda of the session with the client: *"[We have] new ideas every time we meet... Every time we meet, we do an icebreaker and agreement just so [the clients] know what's gonna happen in the meeting."* (L3). Subsequently, depending on the client's needs or preferences, the peer may incorporate activities that allow a client to: (1) just have a conversation: *"Some folks have wanted to talk about their trauma and what has happened. Other folks want to talk about everything but."* (P1). (2) observe and understand their emotions: *"Well, we have a spinning wheel. It's like when you spin the wheel and it'll stop and say 'angry,' then we ask them the question, 'what is making you angry that day?'"* (L2); (3) regulate their emotions in general: *"a video for people with disabilities. A yoga video [that I found]"* (L1); (4) cope in the moment: *"So I'll show them how to do coping skills, like the breathing, that's easy. A lot of people like the breathing exercise."* (L2); (5) play games: *"[The clients] love the Jeopardy! game and they love playing Family Feud. It has questions like, 'what are ways to take care of yourself?' [and] 'fun activities in the summer'"* (L2); (6) do craft activities with physical props: *"I make [self care bags] and sometimes... and then I bring it into the office and then put them in the drawer and if anybody wants to use them, any client we have, we mail them out."* (L2); or (7) do safety planning activities: *"[We] developed a trust tree like that and I use it with.... I think it's, like you can name however many people you want that you can, that you trust. You put it on your leaf and then you say why you trust them. So, when we do that, we'll staple it and we'll mail it to them."* (L3).

3.2.5 Only clients who are not in immediate distress are accepted. The peer support program is neither a counseling nor a therapy program. Therefore people who avail themselves of its services are only those who are far enough along in their trauma recovery to not be in immediate distress: *"The navigators usually ensure that, to the best of their ability, that the [the client] is far enough along in their path to healing or that they've been given the resources that they need, before they meet with [a peer]. The reason for that is that the peers are not counselors, they are not therapists.... So [the navigators] like to ensure as much as we can that before the peer meeting happens, that that person coming into the meeting is, they... are in a place where they are comfortable and safe and having a conversation with the [peer]. So they're not usually in crisis at that point and usually time*

has passed since the assault and before they meet with their peers." (P1).

3.3 Study findings 2: Technology can facilitate distance peer support sessions but these sessions are qualitatively different from in-person peer support.

Next, we wanted to know what role technology already plays in peer support, if any. We identified five main themes related to technology and peer support, which we describe next.

3.3.1 Peer support sessions are also conducted online. Peer support sessions used to be held exclusively in person but since the COVID-19 pandemic, online (Zoom-based) sessions have also been introduced. Contrary to the in-person sessions, the online sessions use PowerPoint slides: *"So the first meeting is like an icebreaker, like a meet and greet, so [the peer is] going to do meet and greets, and [they are going to engage with the client and get to see what [the client] likes.... And then after the first session, we're going to see if [the client] wants to do another one. [If so, the peer, with help from a peer support specialist2] develops another PowerPoint for the next session."* (P5). The participants also brought up the point that PowerPoint slides were only used for online sessions. In-person sessions (which did not use them) just involve conversations between the peer and clients with physical artifacts, as needed: *"So ... it's a conversation and we're just talking... We would also bring things like an iPad and share music or activities that way."* (P2).

3.3.2 Peer support specialists help the peers translate their ideas into PowerPoint activities for the online sessions. The peers and peer support specialists have a collaborative relationship when it comes to online peer support sessions. The peer support specialists are essentially there to be the hands of the peers in creating the PowerPoint slides and to help guide them, if they need it: *"But [the peers] are the primary people who are, you know, coming up with the content and we're just there to edit or guide. If they get stuck, [peer support specialists] can be helpful and make suggestions."* (P7). The extent to which the peer support specialists help a peer depends on the *"level of support they need"* (P7). The peer support specialists also ensure that the content is aesthetically close to what the peer wants: *"Aesthetically, how [the peers] want it to look is really up to them.... I'll say, 'OK, what color do you want? Or you know, what picture would you like to put here?'"* (P7).

3.3.3 Many in-person activities can performed in online sessions as well. Many activities that are done in-person are also conducted online. Some examples include: playing games like Jeopardy, listening to music, and creative activities: *"So like an in-person meeting, they were like making vision boards (a scrapbook feature provided by the online website Canva) about [affirmations] together.... If we're*

online, we still make vision boards online but what we do is like, [the navigator] will bring up a Canva screen and the peers will have like a list of questions [for the clients, which form the basis for the information the navigator will put on the vision board].” (P3). This spirit of creation carries over to physical things as well, such as crafting activities, where materials are sent to the client prior to the online session or brought to the session when in-person: “You know, they also do like arts and crafts and things. So the navigator or the peer support specialist can bring out supplies to the clients and then when we have our [online] session, mail them.” (P7).

3.3.4 Several of the online versions of the peer support activities are not the same and need additional considerations. When peer session activities are conducted online, the activities are often performed not by the client but rather by the staff members, based on input from the client: “Usually, if [the session is] virtual, [the peer support specialists] will [type] because I’m an awful speller but if it’s in-person, the [client] can do it, we’ll have them do it or else we’ll do it with them.” (L3). The same goes for arts and craft activities, which, despite providing the materials to the clients, are rarely done synchronously (and collaboratively) as they would be in-person: “Well, I’ll show them how to do it [online], if they have questions... I’ll reach out to [the navigator], and [they] would email [the clients] afterwards to see if [the client] would be interested in doing [the craft activity] on their own.” (L3). One of the most important considerations when providing content online, which is usually handled by staff members, is to make sure that the content (i.e., the slides) is accessible to the client, given their individual needs: “A standard [the staff members] are trying to keep is having it accessible for people with low vision and different needs with being able to see and be able to read everything.” (P7).

3.3.5 Overall, online sessions are easier to schedule and hold but end up being more about teaching and less about the vital connection between peer and client. Online peer support are easier to schedule and can be held more often than in person sessions: “So do you have a higher follow through [with online sessions]... we can see people more often.” (P2). However, it is not the same as its in-person counterpart. In-person the peers get a lot of contextual information, which is not easy to obtain via a screen: “I read a lot of body language. So I know when they’re getting tired or they’re getting frustrated” (L2). This lack of information also affects the level of trust that can be established between the peer and the client. Further, the conversations in-person are more natural, which invites the clients to interact more on their own: “So I would say conversations were just more natural in-person. And different things would come up. You know, or the client might actually initiate more. I think the client is also more likely to just follow what’s offered in the slide rather than [realize that] there’s always a choice.” (P2). Consequently, online sessions end up being highly structured around the activities put together on a set of PowerPoint slides. They create an environment that more so resembles one-sided teaching or a unidirectional presentation mode rather than an interaction between the peers and the client: “Presenting from a slide changes the way people talk to each other... So one thing that can happen as a peer is that they almost change their tone and the way they talk as if they’re teaching versus having a conversation. I would say that’s the biggest change.” (P2). Despite this significant difference between online and in-person peer support

sessions, the online version has the advantage of being more easily scheduled and the potential to, at least in part, compensate for some of the barriers to accessing peer support. Thus the online peer option can make peer support available to more people with I/DD, which is fundamental in a community that often has limited support structures: “I think the benefit of being online is that folks show up more, like they don’t have as many complications and getting to a meeting” (P2).

4 DISCUSSION

Our aim in this work is to see how technological solutions could facilitate peer support between individuals with I/DD in a post-abuse context. Based on our findings, the current online version of peer support is not equivalent to the in-person experience. It’s much more informational, non-interactive, and can distance the client from the activity. However, given that the online alternative makes peer support available to more people and more often than the once a month schedule of the in-person sessions, we recommend leveraging this benefit while also seeking to move past its current incarnation as PowerPoint slides over Zoom. While this pivot to offering peer support online during COVID-19 was admirable and effective, **given the potential gains from continuing online peer support outside the pandemic context, we recommend designing better virtual alternatives to supplement in-person peer support on an ongoing basis.** One the most biggest drawbacks to how online peer support is currently performed is that it inhibits rather than fosters peer-client interaction. This diminished peer-client connection negatively affects the establishment and maintenance of trust between the two, which is essential for peer support. Consequently, any technology that is developed for peer support needs to promote collaboration and interaction between the client and the peer. Below we mention a few ways to go about fostering this connection.

Individuals in the I/DD community are avid users of smart devices and apps [32]. Therefore, it makes sense to leverage the capabilities and dynamism that apps can provide for online peer support - especially for activities that involve creating or curating information. Leveraging apps for I/DD peer support involves several interesting design implications. (1) How to allow clients and peers to collaborate in real time on activities, such as adult coloring, playing a game, or creating a self care plan? (2) How to design in such a way as to make the app I/DD-accessible, which would allow both peers and clients to use the app independently without needing to rely on a staff member or caregiver? For instance, the app could use LLM-based auto-complete features to help them enter information. (3) How to accommodate clients with various speech abilities? Symbol-based alternative and augmented communication (AAC) systems could help to achieve this. (4) What other approaches would the I/DD population find helpful for technology-mediated peer support? For instance, affective computing could help the peer teach the client how to identify and respond to their emotions.

However, not all peer support activities are information-based and, therefore, conducive to engaging in on a 2D screen. Activities that involve building things or using physical props, like arts and craft activities, may work better in a 3D environment. To this end, social virtual reality (VR) environments (appropriately protected)

can be leveraged to place the client, the peer, and staff members in the same virtual space. The design implications for I/DD-accessible peer support in a social VR environment include the following. (1) How to design an immersive environment where the peer and client can manipulate virtual objects, especially virtual props they can use to create things? (2) How to use the immersive nature of the virtual environment for peer support. VR has the potential to offer various types of immersive sensory activities, for example, those that engage one's sight and/or hearing, which can have a calming effect on individuals with I/DD [29]. (3) How to leverage the virtual environment to allow users to perform activities that are difficult for them in the real world. The VR environment can also offer the experience of many activities and practices, as part of peer support, that would otherwise be unavailable or difficult to achieve, especially for the I/DD population, who often deal with considerable logistic difficulties (e.g., exploring different locales, traveling).

Given that, in the the last few years, VR platforms have become relatively cheap and much more ubiquitously available [2], it is the right time to explore the use of newer technologies, such as VR, for the I/DD community.

5 CONCLUSIONS

Peer support provides an excellent way to help abuse survivors with I/DD to establish a productive connection with peers and use this connection to manage the negative aftereffects of the abuse. However, there are numerous systemic issues that make it difficult for such individuals (i.e., survivors) to access peer support. Consequently, we interviewed 11 people who work at an organization that provides trauma services US and looked into how peer support in the post-abuse context is provided. We found that: prior to the COVID-19 pandemic, their peer support sessions were exclusively in-person sessions that fostered building trust and a productive connection between the survivor and the peer. Since COVID-19, peer support sessions are also provided online. These online sessions make it easier for survivors to participate in peer support and for peers to conduct sessions. However, the online sessions also diminish the peer-survivor connection that is so integral to the success of peer support. Based on these findings, we recommend the design of several types of technologies that could enable online peer support to foster a productive connection between survivors and peers, as in-person peer sessions do.

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