



“I’m Ok Because I’m Alive”: Understanding Socio-cultural Accessibility Barriers for Refugees with Disabilities in the US

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ABSTRACT

The number of refugees worldwide has doubled in the past decade. Data shows a large percentage of refugees experience disabilities and mental health challenges, often exasperated by being exposed to violent and inhospitable conditions at different points in their journeys. There is a need to better understand the challenges that refugees with disabilities face in host countries to inform supportive policy, service, and technology solutions. In this paper, we report findings from interviews with six experts who serve refugees in the US. Participants described resources available to refugees with disabilities and how inadequate language and cultural support systems create barriers to accessing them. They also identified several directions for structural change, including access to comprehensive insurance coverage, early recognition of mental health challenges, and support for navigating the host country’s complex healthcare system.

CCS CONCEPTS

• Human-centered computing • Information Systems • Applied Computing

KEYWORDS

Refugees with Disabilities, Accessibility, Assistive Technology

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1 Introduction and Background

According to the United Nations Refugee Agency (UNHCR), there are currently more than 79 million people who are forcibly displaced worldwide, a figure that has almost doubled in the past ten years [32]. Among this sizable population are 26 million refugees – defined by the 1951 United Nations refugee convention as “someone who is unable or unwilling to return to their country

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of origin owing to a well-founded fear of being persecuted for reasons of race, religion, nationality, membership of a particular social group, or political opinion [31].” Our understanding of the factors that lead to forced migration is evolving and in 2016, the New York Declaration for Refugees and Migrants added “adverse effects of climate change, natural disasters (some of which may be linked to climate change), or other environmental factors” as important factors that by themselves or in combination with other previously identified factors, such as “armed conflict, poverty, food insecurity, persecution, terrorism, or human rights violations and abuses”, can lead to forced migration [34]. Given this landscape, it is likely that refugee numbers will keep increasing and so should the capacity-building efforts of host countries, and governmental and non-governmental organizations whose mission is to support this diverse and marginalized population.

While historically the notion of disability was not included in the 1951 United Nations Convention on the rights of refugees [31], and there has been a disconnect between services provided to refugees and people with disabilities [22], in recent years, UNHCR has begun to strengthen links with organizations serving people with disabilities to improve inclusion and diversity efforts for refugees with disabilities [33]. As part of this effort, the agency now offers specific guidance on how to systematically account for disability in refugee and forced migration populations [32]. These efforts have already resulted in significant outcomes: for example, including specific questions about disabilities during registration time has shown that in Jordan, up to 45% of Syrian refugee households have at least one individual with a disability [32]. Further studies have shown that refugees are more likely to experience acquired disabilities and mental health challenges such as post-traumatic distress (PTSD) due to increased chance of exposure to adverse pre-displacement, displacement, and post-displacement events [6] [27]. Finally, research has shown that refugees often have access to low-cost technologies such as cell phones and social networks that may be used to sustain and develop relationships, find resources and opportunities, and navigate new languages or cultural contexts [17]. The combination of these factors warrants new work in the accessibility research community towards understanding and addressing the needs and desires of this growing and diverse population.

The United States is one of the most prominent resettlement destinations for refugees and currently, refugees represent about 10% of the annual immigration flow into the US [23]. The current study took place during COVID-19 in Baltimore City, a major city

in the Eastern United States, where refugees are provided with social service programs such as direct benefits, medical assistance, health screenings, employment, English learning, and programs specifically for youth and older adults. In addition to government-organized programs, other non-profit organizations, religious institutions, and programs within schools and universities also provide services to refugees.

In this paper, we explore this area by conducting an interview study with 6 experts that provide services to refugees with a focus on understanding the accessibility and health services available to refugees and barriers to effectively using them. We also asked participants about their perspectives on how policy, technology, and service design efforts may improve the use of services by refugees with disabilities. Given the exploratory nature of the research, we decided to ask about both physical and cognitive disabilities and mental health challenges. Our analysis of the data resulted in several recommendations for future accessibility and assistive technology approaches that build on existing technologies likely to be available to refugees (e.g., social networks, low-cost cellphones) [17] for navigating the US health system, maintaining social connections while resettling into a new environment, and receiving improved and consistent language and culture translation support when receiving services. We use the term *mental health* to refer to “cognitive, behavioral, and emotional well-being [9]”, and *mental health challenges* to difficulties that individuals may experience in these domains. We use these terms both to be consistent with language used by our participants and to cover a broader range of experiences that may or may not be caused by a *mental illness*, that refers to specific conditions that may “affect a person’s thinking, feeling, mood or behavior [9]”. In this work, we use post-medical models of disability, specifically the *social* and *human rights models* that recognize the social construction of disability and the role of structural barriers, negative attitudes and social exclusion in the marginalization experienced by people with impairments [11]. The human rights model of disability is compatible and complementary to the social model of disability [21] and differs from it by emphasizing the rights of people with disabilities when designing programs and policies and offering more space for recognizing the intersectional nature of the experience of people with disabilities who might also be impacted by other overlapping categories of power relations, such as ethnicity, gender, or immigration status [11]. Furthermore, some of the early formative critiques of the medical model were raised in relation to psychiatry, creating a direct link between mental health and disability [20]. In recognition of these commonality and in the spirit of solidarity, in this paper, we present findings on physical, cognitive disabilities together with mental health challenges.

2 Related Work

Previous research on designing interactive systems for refugees has explored several applications, including navigating a new language [8] or a new multicultural setting [14], finding accommodation and other resources [25], and accessing health care [28]. Two recent international workshops focused on HCI

and refugees identified several areas where digital technology design can make contributions, including access to services specifically for refugees, including healthcare and education, supporting the integration of refugees into host countries, and supporting them during their journeys to safety [30][12]. Furthermore, the workshops resulted in a set of guidelines for designing with refugees that include continuously re-evaluating research scope, contributing to broader refugee agenda at the local, national, and international levels, and building in flexibility and time for trust-building into the research plan [29].

The goal of many of previous studies with refugees that have focused on technology design has been understanding the impact of different barriers on the experience and transition of refugees to overcome them through new sociotechnical solutions ([16] [15] [5], [2]). For example, in a study of the impact of relocation and forced migration on refugees’ or asylum seekers’ social capital, Almohamed et al. found that refugees who lack social ties in the host community have a significantly higher risk of depression compared to other community members in the same context [3]. They further found that digital communication technologies can have a positive impact on the social inclusion of refugees. In another study, using a set of participatory design activities with refugees, Almohamed et al. identified three factors, cultural adjustment, organizational support, and social activities that contribute to newly-arrived refugees’ social capital [4].

A range of technologies such as translating platforms [8], dietary tracking devices [15], mapping technologies [16], Interactive Voice Response (IVR) radios [28], and mobile applications [5] have been created to overcome specific barriers of social inclusion, language competency, and improving health. For example, building on the knowledge that many refugees have access to low-cost mobile phones, Baranoff et al. designed a cost-efficient mobile service to help refugees navigate their surroundings and get specialized services by using a combination of mobile phones and Near Field Communication (NFC) tags that can be placed in different locations to provide contextualized translated information to users [5]. Another project, Rivertran, explored the design of a “human-in-the-loop” messaging platform that helps refugees navigate language barriers when they arrive in a host country [8]. Another project conducted in a Syrian refugee camp in Lebanon utilized an IVR mobile-based radio show to provide health information specifically curated by and for refugees for camp residents [29]. In the context of refugee camps, several projects have adapted Western models of informal learning and access to digital resources, such as MIT’s Computer Clubhouses [26] and the German Computer Club [1], for use in long-term refugee camps in Palestine and the West Bank. In both of these projects, researchers identify rich opportunities for participants to engage in digital media production and storytelling, and also emphasize the importance of conducting situated participatory research that is aware of the particular characteristics of each setting [1] [26].

Research outside HCI, in refugee and forced migration studies, has studied the experience of refugees with disabilities. For example, in a study with 44 service providers, Choi and Wynn found that communication barriers and lack of knowledge about

mainstream health services were major barriers to accessing services for developmental disabilities for Asian refugees in the US [10]. Other studies of the experiences of refugees with disabilities in the US, have identified additional factors such as inadequate community outreach and cultural differences and misunderstanding as posing barriers in this space as well [7] [36]. Mirza and Heinemann conducted a study with both refugees with disabilities and expert service providers in the US and using a series of interviews, focus groups, surveys, and participant observations found that refugees with disabilities have several unmet disability-related needs that impacted their resettlement experiences [22]. Findings identified the service providers' limited awareness of disability rights and resources and a medical understanding of disability. Other factors included refugees being disconnected from disability service systems, lack of communication and trust between different service entities, and limited cross-cultural understanding in disability service organizations. Similarly, using interviews with service providers and refugees in California, Morris et al. found that the majority of refugees do not regularly access health services, and language and cultural differences impact all stages of access to healthcare services, from making appointments to filling prescriptions [24].

3 Methods

3.1 Participants

We conducted interviews with six employees of governmental and non-governmental organizations that serve refugees in Baltimore City, in the state of Maryland in Eastern US. Table 1 below provides a summary of information about the participants.

Table 1. Participant demographics

ID	Age range	Gender	Ethnicity	Experience (Years)
P1	60's	Male	Palestinian	5
P2	30's	Female	White	8
P3	40's	Female	White and Native American	14
P4	40's -50's	Male	Middle Eastern	4
P5	20's	Male	African	7+
P6	40's	Male	African American	10+

We contacted community organizations, and local, and state government programs to recruit participants and used snowball sampling to find new participants. All participants, except P2, work at non-profit organizations that provide services to refugees, and P2 works at a government agency that does the same. Three of the participants (P1, P4, and P5) arrived in the United States as refugees themselves and draw on their personal experiences as refugees during interviews. We decided to interview experts because we wanted to ensure that for this initial phase of the project, we collect population-level data reflected in the perspective of experts who have worked with multiple

individuals, and also to decrease the burden of participation on refugee families with a member with disabilities.

3.2 Data Collection and Analysis

We conducted remote semi-structured interviews through either Google Meets or by phone. We decided to use semi-structured interviews since they provide an opportunity to gather detailed qualitative information about participants' experiences. We conducted the interviews remotely since the study took place during the first year of the COVID-19 pandemic. Interviews lasted on average 60 minutes. All Participants except P2 received a \$25 gift card upon participation. P2 chose to opt out of receiving the gift card. The study protocol was reviewed and approved by our university's institutional review board (IRB).

We developed an interview protocol based on a preliminary literature review. We piloted the interview with two students to refine terminology and timing before using it in interviews. In the interviews, participants were first asked about their backgrounds and experiences with the refugee population in Baltimore City and Maryland (where the study took place). Subsequent questions were divided into three categories: the impact of disability on refugee families, and the accessibility of disability services and health resources. Within each category, questions were organized into three subcategories, each probing physical disability, cognitive disability, and mental health.

We audio-recorded the interviews, which we then stored in an encrypted online location before being sent to an online service for transcription. The second author independently conducted inductive thematic analysis on the transcripts which was followed by the first author reviewing and refining the themes.

4 Findings

Our analysis resulted in four themes and nine subthemes that we will present next. The main themes included disabilities impacting refugees, available resources and barriers to accessing them, the use of digital technologies by refugees with disabilities, and possibilities for future intervention.

4.1 Disabilities Impacting Refugees

Participants described a range of physical and cognitive disabilities impacting the refugee population in the Eastern United States. Concerning physical disabilities, all participants stated that most of these conditions were acquired through experiencing hardship and sometimes in the process of fleeing and traveling from a war zone. P6 described that "prominent physical disabilities ... are injuries as a result of the travel that refugees have to go through. Oftentimes, they deal with ... being assaulted. So, people that are shot, I've dealt with several people that had wounds that were not healed, or they lost a leg, lost a limb because of either, again, from being attacked or also land mines, things of that nature." Additionally, P1 explained the impact of dangerous journeys as well:

"The physical ordeal of fleeing from a conflict zone, from a war zone, or even before they fled, being picked up by the security forces...and being tortured or suffering war-

related injuries, having been shelled or bombed, shot at, etc. ... all that left them with these acquired injuries.”

P2 shared similar observations of disabilities and medical conditions occurring due to being exposed to war and conflict: “There’s...deafness. There are neurological complications and... complications from gunshot wounds and shrapnel”. P3 had observed a range of conditions known to be related to high levels of stress and anxiety in the refugees she works with, including motor control issues, chronic obesity, malnutrition, high blood pressure, and heart complications. P5 also shared similar observations on the impact of fleeing and transitioning and the trauma and injuries that it can result in, bringing up a similar example to P2 of refugees who lost their hearing as a result of exposure to a war zone.

In addition to physical disabilities, participants described observing a high level of, often undiagnosed, mental health challenges and cognitive disabilities in the populations they work with. For example, P4 stated seeing down syndrome and learning disabilities especially among children. P2 had also met refugees with cognitive disabilities but was unsure about specific diagnosis. P6 specifically described observing mental challenges caused by exposure to difficult conditions, for example in the case of “youth that have malnourishment, which also causes mental and cognitive disabilities as well.” All participants were aware of mental health challenges that refugees experienced, including post-traumatic stress disorder (PTSD), anxiety, adjustment disorders, paranoia disorder, and depression.

Several participants (P2, P5 and P6) explicitly identified the lack of diagnosis for mental health challenges and cognitive disabilities and linked it to cultural stigma towards these conditions. P5 stated, “I feel like there’s a big stigma ... There’s a lack of diagnosis. There might be suspected congenital disabilities, but the families don’t go and actually get them confirmed or actually get them diagnosed and stuff like that.” Similarly, P6 stated, “A lot of the individuals that I work with, it was hard to define what their disability was... they didn’t go to the doctor to be able to get it diagnosed, so it was hard to say exactly that’s what it was.” P6 identified this as a major issue, saying “mental health needs to be put on the same line for the same importance as physical health.” We will revisit the notion of stigma towards disabilities in general and cognitive disabilities and mental health challenges in more detail in section 4.2.

Participants described that in Maryland, refugees generally receive basic medical insurance (Medicare) for the first year and some also qualify for extended insurance (Medicaid) later. P1 described that they also receive three months of financial support, cultural lessons, limited language instructions, help to find employment, and access to other government services. Upon arrival refugees go through two separate health screenings, to assess physical and mental health, at federally qualified health centers. According to P3 this process and its details are different in each state. P3 described the process broadly as “when refugees come through the refugee program, they’re seen overseas by a medical provider first, and they’re given a pretty thorough exam, but then we know that healthcare differs from country to country. So, once they arrive, they have a whole other pretty thorough

health exam. So, people arrive with certain diagnoses and then we see them again and get a little more specialized.” In addition to general resources available to all refugees, in the case of individuals with disabilities or adverse health conditions, specialized resources are allocated in schools and through government programs that provide specialized or intensive case management (ICM), which is a focused and holistic approach to providing support to address specific mental health challenge and social support for the affected person [16]. In addition to governmental agencies and schools and hospitals, other organizations such as non-profit organizations and religious centers, and communities would provide additional support and pathways to resources.

4.2 Barriers to Accessing Health and Disability Resources

4.2.1 Cultural Factors Affecting Access. Participant identified the cultural differences between refugees’ country of origin and the United States as a key factor limiting refugees’ access to disability and mental health services. These differences are sometimes related to how people communicate about disabilities or specific health concerns, for example as it relates to mental health. P4 stated, “I think there’s a stigma that people don’t want to talk...share information about people with disability. And the stigma, I believe, it varies culture by culture... they seem to hide... they don’t talk about it...They don’t share anything about it. And I wish they do because it would be so beneficial...because the cultures that they come from is such an inclusive culture...But when it comes to mental or physical disability, people tend to have some type of stigma.” Participants especially emphasized the impact of culture on the acknowledgment, communication, and treatment of mental health challenges. For example, P1 stated that for most refugees, “culturally, it’s very taboo to have a mental health problem and to seek treatment for it and to admit it and all of that.”

Furthermore, the severity of stigma sometimes depends on the nature of disabilities or health concerns. For example, according to P1 disability is viewed differently based on whether it is acquired or congenital, “[With congenital disabilities it is] considered you’re either possessed or cursed...or something is wrong with you. It’s your fault. They blame the victim if you have a disability... But when people suffer from disabilities caused by torture or war-related injuries, no. Then I think it’s treated as kind of a badge of honor if anything... But if they become unable to work, then I think that probably has a very problematic impact because it’s expected that the man would go out and work.” P5 who is from Kenya himself similarly described how in some refugee communities, there is more stigma towards cognitive disabilities and mental health than physical disabilities: “Especially coming from Kenya, there’s this stigma around mental health and cognitive disability, disabilities in general...there’s this stigma around the community that, ‘Oh, my child has a disability. And thus, I must have done something wrong, or my child must have done something wrong.’ So, there’s that kind of hesitance to getting that diagnosed.... Same as [cognitive disabilities], there’s the cultural stigma of mental health, or mental health concerns

are this made-up phenomenon, that depression is not a real.” P5 went on to identify education as a key tool for overcoming stigma and described how having resources without education would not be effective because, “we’ll have these amazing resources about how to help people, but no one is willing to seek out the help.”

The cultural barriers that prevent refugees from acknowledging or communicating about disabilities or mental health challenges can lead to other obstacles such as getting care in time, keeping a job or taking care of their family. P6 described the impact of lack of diagnosis on delaying receiving services for refugee youth, “it would be youth that were not treated, or had mental health or cognitive disabilities that oftentimes were hidden because of stigma. So, those disabilities were not able to be addressed until they got with somebody that they could trust.” P5 further stated the getting refugees to overcome the stigma of asking for help with respect to cognitive disabilities and mental health challenges would be a major step.

P6 further described how refugees’ difficult journeys made them focus on survival rather than dealing with mental health challenges as they arise which would then lead to exacerbated conditions later on: “But sometimes the lack of proper medical care or adequate medical care that they weren’t taking care of because they were dealing with basic needs for survival. So because those things were not addressed at an earlier stage, they exacerbated it, into now a disability that’s a little bit more permanent.” He further described how trauma can be further amplified when refugees are in a situation where they experience discrimination because “because they look different, or [they] pray different, or [they] speak different.” Finally, he described how complex emotions arising from survival guilt and a desire to preserve self-respect can lead to denying a need for help, with refugees asserting (in P6’s words), “Hey, I’m here. I’m okay because I’m alive.”

P2 further explained that the cultural differences in viewing mental health by both the healthcare provider and refugees create challenges in how important medical information is being communicated, which can impact the way refugees acknowledge and accept treatment:

“The way that a lot of people-- providers in Maryland and the US talk about mental health can be really unhelpful...people think that you think they’re crazy or sort of easily go there...I think if you can sort of cross that divide and sort of have someone really know how to speak honestly, but gently as well, about what mental health services in the US are, it can help a lot... the term ‘mental health’ itself has a lot of baggage for a certain population of refugees that-- it’s not what we mean when we say, but I think a lot of refugees hear ‘mental health,’ and they hear, ‘You think I’m crazy’ or something like that...So having of understanding of what mental health might mean in that culture and figuring out how to talk about it in a way that’s relevant and meaningful [would be helpful].”

In the above comment, P2 is describing an approach to mental health communication that is both direct and at the same time culturally sensitive to ensure that bringing up such a culturally

charged topic as mental health can be done effectively and compassionately.

P3 described that sometimes the cultural nuance of how to communicate about mental health in a culturally sensitive manner is lost by US healthcare providers who may generalize the refugee community as a group that does not understand or want to communicate at all about mental illness: “The issue, I think a lot of times becomes Americans putting the stigma on refugees. We like to say that they come from countries that don’t talk about mental health. Well, if we put that on them, we might be taking away the opportunity for that person to talk about mental health.”

Beyond the negative reductive impact of stigmatizing refugees’ attitudes towards disabilities and mental health challenges, P3 reflected on situations where cultural encounters could lead to decreased stigma about disability. P3 described a shift in the attitudes of a Sudanese refugee who is blind and their family upon receiving culturally competent medical care in the US:

“She’s blind and from Sudan. ... Everyone took pity on her and never thought she’d amount to anything. And then when her family moved here for medical care, as they gain the knowledge that, ‘Hey, she’s going to be able to work someday. She’s in a blind train program. She’s got friends, she knows how to take an Uber places,’ ... that stigma starts to change.”

The cultural disconnect between refugees and US healthcare providers can cause challenges in communication and trust. P2 explained, “[the relationship between client and service provider] depends on the culture. It depends on the family. It depends on the disability. But certainly, there are cultural-- yeah, I mean, some clients don’t like to undress in front of doctor even...there can be some distrust as well about medicines or treatment or sometimes frustration when they go to an appointment, they’re not given medicine.” In the previous quote, P2 is describing a scenario where not receiving medication in a particular situation might be interpreted as a lack of attention or care on the part of the service provider. P2 further described how cultural differences can cause misunderstanding in this context: “I think certain other cultures kind of take their time getting into an issue. And I think especially the American medical system, doctors don’t have much time, can be very direct, not always incredibly warm, especially in very busy clinics where there’s not a lot of time. This isn’t a judgment, but just-- and sometimes, people can feel that doctors hurried or were too curt or didn’t take their time with their child or with whatever. And that can cause them to not want to continue treatment or to go somewhere else.” In other words, cultural differences might lead to misunderstandings that impact the quality of relationships between refugees and service providers.

P6 described several strategies for overcoming cultural barriers to better serve refugees, including making an effort to learn about refugee languages and cultures, undergoing anti-racist and anti-bias training and working with community advocates to build trust: “When I would work with populations, especially in the Syrian population, and especially working with some of the women that needed assistance, they didn’t feel comfortable

talking to me. So, I would talk to one of my allies, a sister and leader ... who would then translate for me what they said in Arabic but also culturally what does that mean." Another strategy P6 used was working with religious figures in the community, "Because a lot of times, especially within the Muslim communities, because the mosque is an essential place that most people go to. So, educating religious leaders with how to give people recommendations to effective social services and not just pray their pain away leading their service [is a good strategy]." Finally, P6 emphasized the importance of personal cultural exchange for trust-building, "Sometimes we need an exchange. ... Sometimes I would come in and I would be anxious as a provider. I'm nervous. I would drink that tea, and man, they're giving me more healing than I gave them. Even though we may look and say, "Oh, it's just tea," they're actually giving you medicine and they're helping to heal you. So also I'm saying, don't just think just because you're coming to help them that you can't receive it. It's a reciprocal relationship." In this quote P6 describes a respectful and kind exchange of tea at a refugee client's house as a trust-building ritual.

4.2.2 Language Factors Affecting Access. According to our participants, another factor related but distinct from cultural challenges are language barriers that pose some of the most difficult factors refugees face in accessing accessibility services, medical care, and public services, in general. For example, when asked what resources are most needed to support refugees, P2 remarked "Interpretation always. I don't think that's the only barrier to refugees accessing mental health or other services, but I do think it's a really big one." When asked about crucial areas of improvement, P6 and P3 both identified the importance of translated resources, and P3 stated "making sure everything is available in refugee languages. Probably better needs assessments of [language needs] ... what are the refugee languages because a lot of times we think-- I mean, 9 times out of 10, when I talk to providers, when they think refugees, they think Spanish. ... There're more people who speak Arabic than Spanish in in [name of city anonymized for review] We need better needs assessments, better documents that in translations should be translated by a professional and then back-translated to the original language to make sure things actually get across in the right way, but at all levels; healthcare, police public health, public transportation, insurance, everyone needs to work together to make sure that their topics are being covered in those languages so that refugees are getting the right information and not third-hand information from their mothers, cousins, sons."

Language barriers are most prominent in the presence of a communication gap between healthcare providers, including therapists and assistive technology experts, and refugee families, and can manifest in verbal and written communications that may provide vital information to refugees. Our participants identified two main factors contributing to these barriers, limited language support, and stakeholders' (i.e., refugees and healthcare providers) limited uptake of services to overcome language difficulties.

By limited language support, we refer to the lack of adequate resources for refugees to overcome language barriers to accessing healthcare and accessibility resources. Resources that may be

effective for overcoming these barriers include access to interpreters, multilingual healthcare providers, and technologies that help with translation and interpretation, among others. As described previously, in Maryland, several resources are specifically allocated for supporting refugees with disabilities and health concerns. However, according to our participants, these resources cannot be utilized effectively if refugees are unable to communicate with healthcare providers. As P3 described "Especially in [name of city anonymized for review] area - we have the best healthcare in the world. People come from all over the world to go to [two internationally known local research hospitals]. And so, when we're thinking about healthcare and adaptive technologies. We can develop the best things on earth, but if it isn't in a person's native language and they're really truly able to understand what's going on, the outcomes, the health outcomes are not going to be as good." P3 additionally suggested that to overcome this obstacle healthcare providers should incorporate language services into their practice:

"it's going to come back time and time and time again to language access, to having good providers in whatever service they're in ... having them be competent and confident in using professional interpretive resources so that they can communicate better with the client. The client walks out of the office fully knowing what the treatment plan is, what the diagnosis is, what's expected of them, where they can get resources."

P4 expanded on this idea further explaining that sometimes even interpretive services are not enough and more fundamental support, in the form of more bilingual staff is needed:

"Maybe it would just be much easier for the disabled person seeking the resources advantage to have someone from that resource to be multilingual because I believe by having an interpreter prolongs a lot of services."

P2 emphasized that interpretation services can be impactful but sometimes not enough because in addition to language training cultural understanding and communication are also important and something that is currently not emphasized by many services. P2 described that "having good interpretation all the time would be really helpful. And obviously, some sort of training on-- and I know organizations, partners, some medical facilities do this in [name of city anonymized for review]. But yeah. Trainings on, 'This is a population I work with. These are some needs that they have,' and just an understanding that the way that you communicate might not be the best way that they might understand and try to think about that and amend it if needed." P2 and P4 stated that access to services such as more multilingual healthcare workers and/or culturally competent interpreters can be key to overcoming this challenge. P6 emphasized that to be effective language teaching services have to be customized to the needs of refugees, "But even though English as a Second Language (ESL) classes are very common, [it is important] to have them within specifically Muslim refugee populations that are speaking Arabic or Urdu ... it's extremely important to have those services that are a little more culturally competent."

The second factor that participants identified as contributing significantly to difficulties arising from language barriers is stakeholders' limited uptake of services to overcome language difficulties. Participants described this lack of buy-in for both healthcare providers and adult refugees. P1 stated that many adult refugees do not prioritize learning English because they focus on overcoming other challenges like finding a job and supporting their families. P1 stated that in the long run, not prioritizing learning English can have generational impacts for refugee parents and their children and outlined some communication challenges that difficulties with English can cause:

“One of the most basic things that actually impacts [refugee parents] is the type of the communication that they get, let's say, from their child provider, like, would want to share some information about the child development with the parent, and the parent would not have the access to read and understand the communication that was sent out to them.”

P5 agreed that language barriers pose major challenges and also added that the amount of information that refugees are exposed to amplifies the issue, “because it's just overwhelming, the amount of information that is thrown at them. And it's even more overwhelming when it's information that they're not able to, or they don't have the tools in order to go through.”

In his opinion, P1 believed that establishing mandatory language training by the government for incoming refugees might help with this issue. In contrast to P1, P3 saw the main issue as a shortcoming of the uptake of service on the healthcare provider's side. She emphasized that though there are laws in place to make healthcare providers provide language services and support, they did not see this being enforced and therefore these services, though they may exist, are not provided and used by healthcare providers. P3 expanded further on this, stating that a possible solution may lay in the enforcement of legislation:

“Enforcement [of The Americans with Disabilities Act] did not come until lawsuits happened and people complained ... So, until people really caused the little bit of noise, that law was there, but it was not being enforced. And that's kind of what we're seeing with language access so that there are laws and legislations delegating this...definitely a gap in the fact that it is required by providers, but it's not being enforced.”

P5 also pointed to the issue of health-related correspondence being issued only in English which makes it difficult for refugees to know the content of the letters without help. For example, P5 stated that “Other navigation I've had to help families with is just understanding the letters that come from their insurance agency. Mostly from a point, the parents are just concerned that they want to know it's not a bill.” P5 further asked: “Why do you think that they find cost to be an obstacle if oftentimes they have some sort of insurance or support?“, indicating that language difficulties prevented refugees from accurately estimating the cost of a service by taking into account insurance provisions.

4.3 The Role of Digital Technologies

4.3.1 Current Technologies Used by Refugees. When discussing current technologies used by refugees with disabilities, P1, P3, P4, P5 and P6 emphasized the importance of using cell phones by refugees, and its positive impact. P1 described how refugees he worked with “tended to access information, including managing their healthcare treatments with their phones. Their smartphones were very critical.” P4 expanded on how cell phones allowed refugees to communicate with each other and provide opportunities for social interaction which can be very beneficial in their adjustment to a new country: “I've seen that by them having some type of cell phones or some type of a device to communicate with the family either overseas or their phones in other states has helped them a lot better to resettle in this country.” Furthermore, P4 stated that having access to cell phones can help refugees maintain social connections: “For those who are actually have experienced some type of trauma, it's good to see that they could reach out to their friends and families elsewhere.” P5 also emphasized the importance of specific phone applications, such as WhatsApp and Facebook that help with social inclusion amongst the refugee community:

“WhatsApp is highly used by nearly each and every one of my families. It's what they use to contact people back home. It's what they do to FaceTime...another one is Facebook and Messenger, that have been able to help them keep in touch and keep that interaction with their friends and families, and also the communities that they're forming here in the States.”

P5 further described how the use of digital technologies helped refugees stay connected with their communities both locally and overseas but that despite the possibility of creating connections with communities different from their own, they tended to socialize mostly with people with similar backgrounds.

P3 and P5 shared how access to a cell phone can mean access to assistive technologies available for it. For example, P3 said, “I'm thinking of my blind client's telephone. There are special [assistive applications] just for blind people that have textured screens and different touch patterns to do different tasks. That has been great.”

In addition to assistive technologies, participants described a range of applications that help refugees overcome language barriers, access medical care and support and socialize and transition into a new country. P1, P3, P4, and P5 described language applications such as Google Translate as particularly helpful. For example, P4 said, “I believe Google Translate has made lives of all the refugees, very, very less challenging ... For example, [in the] case of an elementary schooler who gets mental education services from a school, they will send an email to the parents in English, and whereby the parents would then convert the emails into their preferred language through Google Translate. So, I found that to be extremely helpful in terms of getting the information correctly.” P3 also mentions applications that allow refugees to gain medical care with a translator through an online platform, “Ad Astra has this app where I can get into my phone, I can make all the appointments for language access, and then I can

call the client on WhatsApp. If we're doing a Zoom Meeting on WhatsApp or whatever, I can give the link to the interpreter, and the interpreter will pop up on our screen and we'll interpret for the session that I'm going to do for the client."

P3 described how with proper language support refugees can access a wide range of applications and services using their cell phones, drawing on the specific case of a client who speaks Arabic: "Her phone has the ability to be programmed in Arabic, which allows her to use it pretty [much with everything] -- she orders Uber, she makes her own doctor's appointments. She gets on YouTube. So, that language access capability on there, super important". P4 described how visual media, such as streaming video, are easier to access for refugees even if the content is not in their native language: "If they want to learn something new, they would just go to YouTube look something up. It could not be in their preferred language, but because it's a video-- so they would just watch and just learn something new." P5 built on this concept by stating that these applications also provide opportunities for service providers to learn language and cultural skills to help them better serve refugees.

P3 also described how remote applications that offer resources for people with mental health challenges can help reach more users:

"The digital platform for providers to see patients for mental health has been a life-saver. ... there're so many cool mental health apps popping up all over the place. Biofeedback tools, CBT tools, trauma symptom check-in tools.... Virtual reality for exposure therapy for PTSD.... And with the right therapist explaining very thoroughly and the language access capability, there's no reason those things couldn't be helpful to refugee clients as well."

Here, P3 expresses hope and excitement for emerging technologies to support mental health but is also careful to mention for them to be effective, they need to be combined with work with therapists and proper language support. She gave an example of how translating an application for post-traumatic stress disorder (PTSD) into Spanish made it more usable for refugees:

"The VA's [US Department of Veteran Affairs] PTSD app [PTSD Coach] ... It's a fantastic tool, but the Spanish speakers couldn't use it when it was in English, right?... So now they've rolled it out in Spanish, and Spanish speakers are using it. And so what I think about technologies for mental health as if it's good and if it's data-driven, and if the outcomes are good, and they want to be built for-- I would see that it's better to adapt those things with integrated language access than to redevelop the wheel."

Both P3 and P2 also described how online platforms can be used for creating and sustaining online support groups. For example, P2 stated, "I know [local university] has an online support group for people with ataxia. And so yeah, I know some people who could utilize that as well. There's online groups for refugees who

are hearing-impaired which has been helpful." P3 described online support groups that have interpreters present:

"there is an organization called Asylee Women Enterprise, and they have the evolved. They've gone all virtual for COVID...They had a therapy group once a week, and interpreters were provided for all those activities. Now, all those activities have gone online...So there's a morning meeting on Zoom for all the asylum-seeking women. And they're from different countries all around the world. And there are interpreters provided. So that's one way they're still connecting with each other, even though they can't see each other [in person]."

4.3.2 Opportunities to Improve Technologies Used by Refugees.

Participants described several scenarios where more language integration, creating specific resources for refugees, and making existing ones accessible and engaging with better design could improve the usability of existing technologies. P2 described, "For clients who aren't literate in English or any language, literacy itself is a challenge for using somewhat complicated technologies. And then even for the clients who are literate, even if they know some English it can be difficult to navigate certain technologies." To overcome these challenges P3 suggested exploring the design of, "adaptive phones that are able to be used in different languages or [who interface can be adapted] for different health issues or mental health issues." P3 was quick to mention that sometimes integrating existing applications with other translation add-ons (e.g., Google Translate) can replicate the shortcomings of the translation technology or result in a complex interaction not suitable for use in a medical context: "People developing apps that may have language integration built-in, [need to consider if it] is that being built off Google Translate because we all know the sort of shit-show that can occur when we use Google Translate. So, who wants that to happen when you're explaining a medical procedure?" In this quote, P3 is expressing frustration with translation gaps and inaccuracies that she has observed refugees grapple with when using Google Translate. Similarly, P5 described the tradeoff of using the application, "there's still definite gaps ... There're languages in our communities that are not facilitated. And sometimes it just doesn't do as good of a job as it should. Our community is slightly dependent on it because the fact that they're not aware of any other better or more useful alternatives." Finally, P4 described a shortage in applications specifically designed for refugees with disabilities and that for few that exist, "they are not in the language that is preferred by them."

Among our participants P5 had several concrete suggestions for applications specifically designed for refugees and service providers. For example, he described an opportunity to create therapeutic and e-health applications, especially to support mental health, that are specifically tailored to the needs of refugees, "Having platforms where refugee communities can, especially [refugees with mental health issues], have the digital technologies to have someone to talk through things with would be very helpful." P5 gave the example of TalkSpace, a remote therapy platform, as an example of a platform that can be customized to meet the needs of refugees. P5 further described an opportunity to use digital platforms to spread destigmatizing

information on mental health and cognitive disabilities, “spreading information, so that the community knows, or people and the refugees know, that it is important to seek out that help.”

For service providers, P5 described a database for use by service providers that would list all services and resources available and whether they can be covered by insurance.

P5 also emphasized the importance of providing customized one-on-one support maybe through a remote platform like Zoom to refugee students with cognitive disabilities, “having that one-on-one support like Zoom, having a teacher who’s dedicated and is trained to deal with those kind of disabilities, and is able to help them guide through the academic coursework.” P6 also described a need for more online resources that are inclusive of the needs of people with disabilities specifically to help refugees transition into a permanent state after arrival into the United States.

Additionally, participants discussed the importance of developing accessible and interactive technologies, for example by including more animations, interactive videos, and other elements that provide multiple forms of media for users to engage with. For example, P3 mentioned, “with technology, making sure there are a lot of pictures, a lot of explanation, extra explanation ... it’s not just to input data into Google Translate and then it projects your preferred language, but also to see more like animation of a person speaking out other than someone just to read.” P4 shared their experience working with an individual with down syndrome trying to use mobile apps, and stated that “a simpler way to make an app much more interactive for people with Down syndrome ... would be very, very helpful.”

4.3.2 Access to Technology Training and Highspeed Connectivity. Participants emphasized the need for training refugees on how to use digital technologies to effectively find and utilize resources. P6 identified access to cellphones as a “lifeline” that needed to be provided to refugees upon arrival both to be able to navigate local resources and also stay in touch with relatives overseas via applications such as WhatsApp. P1 believed that government-run, or sponsored technology training programs could better prepare refugees to navigate online resources:

“Like Canada...they give them a year of complete support while they learn English or French, depending on which province they’re living in. And they provide them with little tablets so that they can access the technology. I think tablets are a great means to do that, you know...Distributing tablets and then maybe laptops.... The government needs to probably subsidize [training services] and provide them not only with the hardware and the software, but the skills training to use it. So that will make them feel more socially included and access the services that they desperately need and so forth.”

P1 further emphasized that older refugees might need more intensive technology training, “Young people acquire language and culture at a much more rapid rate than [older] people. So, I think it’s important that to give the adults more care. And technology would be part of that.”

Another challenge that refugees face in effectively using technology is access to affordable and high bandwidth Internet connectivity. For example, P2 stated:

“Not everyone has Wi-Fi at home or in a plan that allows them to participate. So, I do think they’re beneficial if you can sort of get over all the humps to getting there.... A lot of these online resources are video-based or-- at least in my experience... the ones that I’m familiar with are Zoom-based, video-based that uses a lot of data if all you had was a phone plan. So, people really need Wi-Fi at home or their neighbor’s login. But a phone plan with the unlimited data, just not everybody has that.”

Here, P2 emphasizes that just having connectivity is not enough and that refugees also need high-bandwidth and affordable Internet access. P5 also described how receiving and effectively setting up WiFi connectivity can be difficult for refugees and how his organization helps with, “At the beginning of the pandemic, there was a Comcast package [Internet Essentials] that was slightly cheaper, where they’d only have to pay a lower amount per month. And we try to get each, and every family set up at least with that.”

5 Discussion

Participants pointed to a disconnect between refugee services and health and disability services, that resulted in health professionals not being equipped with a deep understanding that refugees with disabilities may face, and for refugee services professionals not having sufficient tools or training to deal with issues related to accessibility or health. We posit that this dilemma, that is also observed in previous studies with refugees [28], can be understood from an intersectional perspective that places the experiences of refugees with disabilities at the intersection of multiple overlapping categories of power relations, disability and immigration status [24]. Viewed from this perspective, it becomes clear that the resources and training of experts serving only people with disabilities or refugees will not be adequate to address the needs of people how are both refugees and have disabilities. Furthermore, refugees in the US and beyond, have a long history of experiencing discrimination and othering with differences in their physical appearance or behavior used to categorize and target them [30]. This history also needs to be considered in relation to why many refugees are reluctant to be identified as having a disability.

All participants described the existence of cultural misunderstandings between refugees and service providers which often have roots in different types and levels of stigma towards disabilities, especially cognitive disabilities and mental health disorders. Participants described how this can lead to reluctance on the part of refugees to receive timely diagnosis and help for themselves and their children, and how it can also result in service providers communicating ineffectively about conditions and services with their clients. Several participants (P2, P3, P5 and P6) described the need for reciprocal trust-building activities and resources that both help service providers develop empathy for refugees’ perspectives, and for refugees to overcome stigma and

unhelpful attitudes towards disabilities. While a number of possibilities exist in this space, we particularly find the strategy of working with community advocates, cultural institutions in refugee communities (e.g., places of worship), and partaking in cultural exchange (e.g., through food, stories, etc.) – with some possibilities for developing and using supportive accessible digital media mechanisms such as podcasts, YouTube videos, etc. – promising in this space. Another related suggestion by P3 identified the need to better incentivize service providers to use proper language services (which is already mandated by law in Maryland) when helping clients. Finally, creating opportunities for health care and refugee services experts to better connect and interact with each other and learn about better ways that they can support common clients is promising. In the future training programs, informed by intersectional perspectives that recognize the unique nature of experiences that are impacted by the interplay of both disability and refugee status can help professional service providers improve their capacity to empathize with and better serve their clients.

Participants were generally optimistic about the use of technologies to help refugees navigate health resources and services. They shared that many refugees already use mobile phones and tablets and are familiar with worldwide services, such as YouTube or Google before arriving in the United States. They identified several applications used by refugees to navigate services and resources, including Google Translate (P3 and P4), Zoom (P3), YouTube (P3), and PTSD Coach (P3). The first two applications are general purpose and can be used in combination with others that are focused on accessibility and assistive technology. While P3 and P4 described scenarios where Google Translate allowed refugees to communicate with their provider, as well as translate important documents and messages, they also stated that its use entails some difficulties, including the introduction of the complexity of using multiple apps at the same time or in the presence of a medical professional and the presence of errors and incorrect translations. Zoom also was described as a platform used to access medical care and support, such as therapy appointments or general check-ups, support group meetings and online community gatherings. While helpful, especially in cases when difficulty accessing transportation to medical services existed, this online platform also posed limitations since practitioners could not physically examine their patients. Similarly, YouTube was also used as a general-purpose resource to help watch tutorials, pick up language skills, and gain general knowledge about the host country's new culture. In contrast, participants the special purpose PTSD Coach provides multilingual resources for seeking and receiving mental health support and was described as useful for refugees P3. While developing online resources and platforms that provide accurate and up-to-date information for refugees is invaluable, we also believe that the ubiquity and existing use of YouTube and similar platforms (e.g., WhatsApp) by refugees indicate an opportunity to support content creation on these platforms specifically by refugees themselves who have navigated the host country's systems already for other refugees who might be facing similar questions. Previous research has shown that refugee youth often

help their families navigate resource in new host countries [19] and a program to train and support them develop resources in this space for their fellow refugees might prove successful. Furthermore, some of the obstacles in using existing resources can be overcome by improving on the features of useful applications such as Google Translate or PTSD Coach, coupled with cultural literacy training for healthcare providers and refugees on how to effectively use them. Our findings also identify opportunities to improve translations of key information which when mistranslated or translated in confusing or unfitting cultural terms (e.g., by automated systems) can create barriers. As previous research has argued (e.g., [35]), this issue is more pressing at the time of crisis, such as the COVID-19 pandemic. With respect to online resources, our data points to the need to create clear, multilingual, and accessible online resources that can help both refugees and service providers find accurate, up-to-date, and easy to understand information on how to address specific physical and cognitive disabilities, mental challenges and health conditions for refugees in the US.

6 Conclusion & Future Work

Refugees with disabilities face amplified challenges already present in arriving and settling into a new country. In this project, we conducted interviews with experts who work with refugees to better understand the challenges refugees face concerning accessibility and receiving needed healthcare services. According to our participants, language and cultural differences form the majority of barriers that refugees face. These barriers translate to a range of factors including stigma towards seeking and receiving mental health services, effective communication and trust-building between healthcare professionals and refugees, and difficulty using digital resources that are available in a limited number of languages, among others. Participants also provided several recommendations including developing culturally sensitive accessibility resources and services, better translation services that can be used safely and efficiently to access disability services, improving the cultural training or healthcare service providers, and better connecting refugee services and disability services organizations, among others. We believe these findings provide much insight and inspiration for developing new solutions in the future and improving existing ones that are sensitive to the needs of refugees with disabilities and mental health challenges. Additionally, we hope that the current project inspires future work that explores this important and understudied area.

A key limitation of the current paper is that refugees themselves were not directly involved in the research. In the future, we plan to conduct a series of Participatory Design workshops with refugee families that focus on understanding their perspective towards accessibility, access to healthcare services, and assistive technology. These workshops will focus on directly engaging with refugees with disabilities and their families to better understand their lived experiences. With this insight we plan to explore socio-technical solutions designed in collaboration with the participants.

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