

Pathway Towards Independent Living: Understanding the Latine Experience with Disability in Southeastern Minnesota



Prepared for:

SEMCIL

SE MN Center for Independent Living, Inc.

Prepared by:



Hispanic Advocacy and Community Empowerment through Research

Table of Contents

About Hispanic Advocacy and Community Empowerment through Research (HACER).....	2
Executive Summary	3
Methods.....	3
Findings.....	3
Conclusion.....	3
Introduction	4
Methods.....	5
Findings.....	6
Focus group participant demographics	6
In-depth interviews participant demographics	6
Objective 1: Definition and Community Perceptions.....	7
Participants defined disabilities as an impediment limiting aspects of their lives.....	7
Participants described instances in which their community members have made hurtful comments.....	8
Objective 2: Experiences, Challenges and Barriers.....	8
Participants described their experience with having a disability as having a great impact on their life.	8
Participants experienced barriers due to their legal status and language needs.	9
Objective 3: Existing Support and Needs.....	10
Participants receive their primary support from family and community members.....	10
Participants have many needs and require access to services to better achieve an independent life.....	11
Objective 4: Engagement Strategies and Promotional Services.....	12
Participants value trust and prefer organizations that share similar language and culture.	12
Participants seek resources and information online and through word of mouth.	13
Discussion	14
Limitations	15
Conclusion.....	15
Recommendations.....	15
Bibliography	17
Appendices	18
Appendix 1: Focus group protocol.....	18
Appendix 2: In-depth interview protocol	20
Appendix 3: Participant quotes	23

About Hispanic Advocacy and Community Empowerment through Research (HACER)

HACER's mission is to provide the Minnesota Latine¹ community with the ability to create and control information about itself in order to affect critical institutional decision-making and public policy. General support for HACER has been provided by Minnesota-based philanthropic organizations and the Minnesota Council of Nonprofits.

Executive Director: Rodolfo Gutiérrez

HACER 155 Wabasha St. S., Ste 105

St. Paul, MN 55107

954-240-0821

www.hacer-mn.org

This report is not copyright protected. However, HACER and Southeastern Minnesota Center for Independent Living, Inc. must grant permission for the reproduction of all or part of the enclosed material, upon request. Information reprinted with permission from other sources would not be reproduced. HACER and Southeastern Minnesota Center for Independent Living, Inc. would appreciate acknowledgement, as well as two copies of any material thus reproduced.

The content of this report is solely the responsibility of HACER and does not necessarily represent the views of Southeastern Minnesota Center for Independent Living, Inc.

Suggested reference to this report is: Yañez, M., Lara, E., De La Rosa Mateo, C., Gutierrez, R. (2023) *Pathway Towards Independent Living: Understanding the Latine Experience with Disability in Southeastern Minnesota*: HACER, St. Paul, MN.

HACER Staff:

Rodolfo Gutiérrez (Executive Director)

Carolina De La Rosa Mateo (Director of Operations)

Gabriela Hanzel (Administrative Director)

Ericka Lara (Research and Evaluation Coordinator)

Jacqueline Portillo (Administrative Assistant)

Mónica Yañez (Research Associate)

Alex Jensen (Research Associate)

Patricia Mudoy (Research Associate)

Rodrigo Escobar (Research Associate)

Rodrigo Gutiérrez (Research Associate)

Deisy Cañon Lovera (Southern Community Outreach Coordinator)

Zadkiel Molina (Digital Communications Manager)

Estrella Ramírez (Digital Communications Specialist)

¹ Latine (latn'ā) is a gender-inclusive term for those with origins in Latin America; it is synonymous with Latinx. HACER chooses to use Latine to demonstrate inclusion and not as an imposition on others.

Executive Summary

The Latine community with a disability makes up an average of 9.1% of the Southeastern Minnesota population. This number has increased in the last decade. Although literature is limited, studies show that disability disproportionately affects communities that have been historically marginalized – including the Hispanic community (Balcazar, Magaña, & Suarez-Balcazar, 2019). This population has unique needs as well as particular barriers that preclude them from attaining a more independent life. This study underscores the importance of taking these factors into consideration when allocating resources to support Latines with disabilities in Southern Minnesota.

Southeastern Minnesota Center for Independent Living, Inc. (SEMCIL), partnered with HACER in this qualitative research project to collaboratively engage and support the Latine community with disabilities in this area. The aim was to identify and learn about the challenges and barriers to achieve more independent living.

Methods

HACER conducted one focus group and 10 individual in-depth interviews with people living in Southeastern Minnesota that either self-identified as having a disability or knew someone who has a disability. Both the focus group and the individual interviews were conducted in Spanish with participants that self-identified as Hispanic and/or Latine. In collaboration with SEMCIL, HACER developed a series of questions to understand the Latine community's definitions and perspective on disability, experiences and barriers, support and needs, and strategies to engage the community and enhance service promotion. In addition to the qualitative study, a descriptive analysis was carried out to better understand the demographic composition of the Latine population with a disability in Southeastern Minnesota.

Findings

The study found that participants defined disabilities as impediments limiting various aspects of life, often making individuals feel incomplete. Hurtful comments and discrimination from others were reported, contributing to feelings of isolation for the participants. However, participants suggested there was some improvement in the Latine community's acceptance of disabilities. Disabilities were seen as impactful, affecting mental health, and creating emotional and financial challenges. Immigration status and language barriers also complicated access to resources and services. Family and community support were crucial, with trusted individuals playing key roles in connecting participants to resources. The study highlighted the need for culturally relevant and accessible services, focusing greatly on trust and understanding of language and culture.

Conclusion

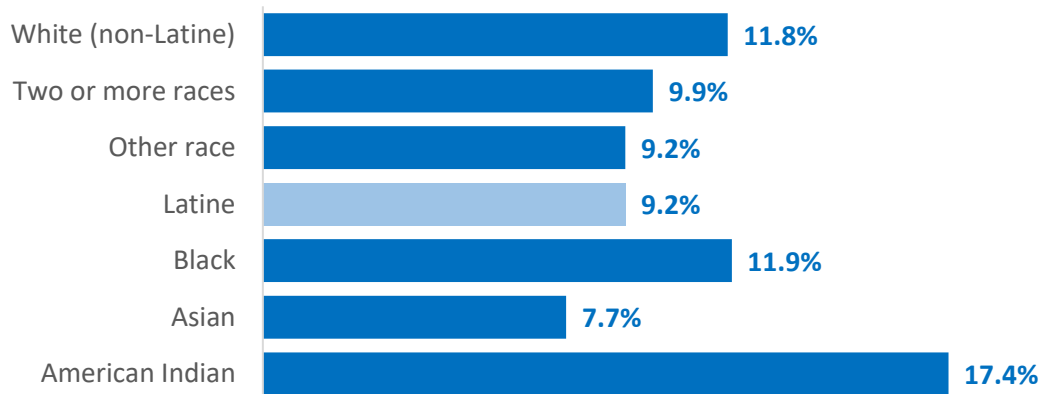
Latines living with disabilities, along with caregivers and family members, encounter distinct challenges that often exceed those faced by their white counterparts. These challenges stem from language barriers, cultural norms, and prevailing stigmas. To enhance accessibility to disability services within these communities, it is important to adopt comprehensive strategies such as producing translated materials, offering culturally relevant programs, organizing community outreach events, and collaborating with local leaders and organizations. By implementing these recommendations, we aim to support SEMCIL's mission of expanding service accessibility to the Latine community. It is our hope that this study will support SEMCIL's efforts in creating a more inclusive and supportive environment for individuals with disabilities and their families.

Introduction

Founded in 1981, Southeastern Minnesota Center for Independent Living (SEMCIL) has been dedicated to serving the Southeastern region². SEMCIL is a non-profit organization comprised of individuals with disabilities and collaborates with others to comprehend the needs of people with disabilities, explore options for care, and develop goals. By upholding their values of dignity and well-being, SEMCIL extends its services without charge to individuals of all ages and backgrounds who self-identify as having a disability. As part of their new initiative, SEMCIL partnered with Hispanic Advocacy and Community Empowerment through Research (HACER) to understand the experiences of the Latine³ community with disabilities in Southeastern Minnesota through their own cultural lens and identify the unique areas of their life that required the most support.

Disability disproportionately affects communities of varying racial and ethnic makeup. The existing research and information concerning the Latine community with disabilities is scarce – greatly in part due to potential underreporting caused by “sociocultural barriers” – restricting an understanding of the community’s experiences and needs and not enough data to represent the Latine community. As the Latine population continues to rise in the U.S., so does the number of Latines with disability (Balcazar, Magaña, & Suarez-Balcazar, 2019). Data suggests there is a risk for Latines to develop a disability in their lifetime specifically due to their working conditions, quality of life, health care access, and immigration status. Within the same breadth of discussion, Latines in the U.S. with any disability are more likely to live in poverty than their white and Asian counterparts and less likely to be active in their communities, be fully employed and live independently (Balcazar, Magaña, & Suarez-Balcazar, 2019). These overarching themes can be applied to Latines living in Minnesota as the state ranks one of the worst health disparities by race in the country (Vanek Smith & Garcia, 2020).

Figure 1: Minnesotans with a Disability, by race and ethnicity (2021)



Source: Minnesota Compass, 2021

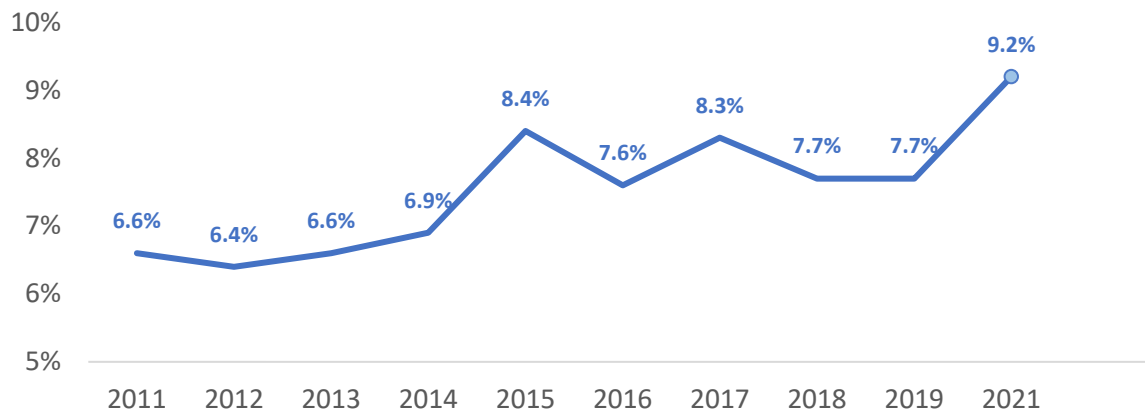
As of 2021, individuals with a disability make up a total of 11.5% of Minnesota’s population, with the Latine community comprising 9.2% of that portion (see Figure 1; Minnesota Compass, 2021). Southeastern MN also shares a similar percentage (9.1%) of Hispanics/Latines that self-identify with having a disability (U.S. Census Bureau, 2017-2021). Notably, the number of Latines with a disability has shown an upward trajectory in the state. Over the decade spanning from 2011 to 2021, disability among the Latine community has seen a 2.6 percentage

² In this report, the Southeastern region is described as the following counties: Dodge, Fillmore, Freeborn, Goodhue, Houston, Mower, Olmsted, Rice, Steele, Wabasha, and Winona.

³ Latine (latn'ā) is a gender-inclusive term for those with origins in Latin America; it is synonymous with Latinx.

point increase (see Figure 2; Minnesota Compass). This trend signals a need to pay more attention to the specific needs of this growing community in order to better serve them in the future.

Figure 2: Latine Minnesotans with a Disability, by year (2011-2021*)



Source: Minnesota Compass, 2021
*Year 2020 did not have valid data available

This report hopes to share the unique needs and experiences of the growing Latine population with disabilities across the Southeastern counties and to help personalize culturally relevant services to achieve a more independent life.

Methods

In collaboration with SEMCIL, HACER developed a mixed-methods research study aimed at understanding the needs and barriers experienced by the Latine community with disabilities to personalize the support needed to achieve a more independent life. To fulfill this goal, a protocol (see Appendix 1 and 2) was created with a series of questions with the following objectives:

1. Understand how the Latine community defines and perceives disability.
2. Explore disability experiences, challenges, and barriers within the Latine community.
3. Assess existing support services and needs.
4. Develop effective strategies for engaging the Latine community and promoting services.

HACER facilitated a focus group with people living in Southeastern Minnesota that either self-identified as having a disability or knew of someone who has a disability. The focus group was conducted in Spanish and consisted of participants that identified as Hispanic and/or Latine. For their engagement, participants received an incentive in the form of a gift card. Due to limited registration for the focus group, and considering the sensitive nature of the topic, it was agreed that in-depth individual interviews would be a more productive avenue to reach participants and would provide a safer space to discuss the topics.

Ten in-depth individual interviews were conducted by HACER in Spanish with the same eligibility criteria as the focus group participants -- identity, region, and self-identifying or knowing someone with a disability. Interviews sought to individualize the conversation and create a more comfortable environment for participants to share their experiences outside of a group setting. Interview participants received an incentive in the form of a gift card for their contribution to the study. The focus group and individual interviews were facilitated using a protocol with the same set of questions. Both methods were also transcribed and analyzed using NVivo qualitative analysis software.

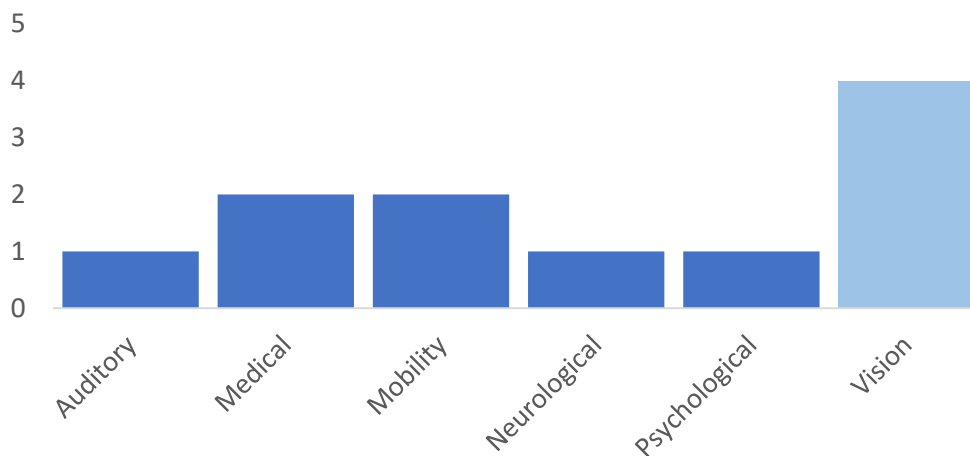
Lastly, in support of the qualitative data collection and analysis, HACER conducted a descriptive analysis drawing upon data sourced from external references to further inform on the demographic composition of the Latine population with a disability in Southeastern Minnesota. A short literature review was also conducted to provide additional support to the socio-cultural context. The descriptive analysis visualizations were done through Microsoft Excel.

Findings

Focus group participant demographics

The only focus group of the project had a total of five eligible and participating individuals. The five participants completed the required consent form to join the conversation. All participants self-identified as Hispanic/Latine and as female. Almost half of the participants (n=2) were between the ages of 35-44, all lived within the eleven-county Southeastern Minnesota region, but most lived in Rice (n=3), and the rest lived in Dodge County (n=2). The majority (n=4) self-identified as having a disability; the last participant said they knew someone with a disability. The most frequently encountered disability, whether by the participant or someone they knew, was visual impairment.⁴

Figure 3: Disabilities encountered in the focus group



In-depth interviews participant demographics

A total of ten interviews were conducted with eligible participants. The ten interviewees completed the necessary consent form to participate in the conversation. All participants self-identified as Hispanic/Latine, and the majority (n=8) identified as female. Half of the participants (n=5) were between the ages of 25-34. Almost all participants (n=9) lived within the eleven-county Southeastern region, but most lived in Rice (n=4) and Dodge County (n=2). One participant at the time of the interview did not live in one of the eligible counties, but lived within the Southern Minnesota region, therefore still accounted for. Most participants (n=7) did not identify with having a disability but

⁴ Based on the types of disabilities categorized by Indiana University: vision, mobility, auditory, neurological, cognitive, medical, and psychological disabilities (Indiana University, n.d.).

knew of someone or cared for someone with a disability. The most frequently encountered disabilities, whether by the participant or someone they knew, were psychological and vision impairments.⁵

Figure 4: Disabilities Encountered, interviews

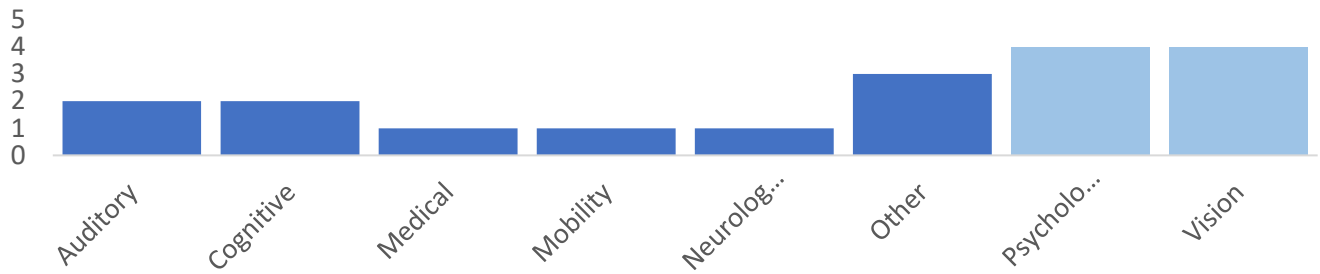
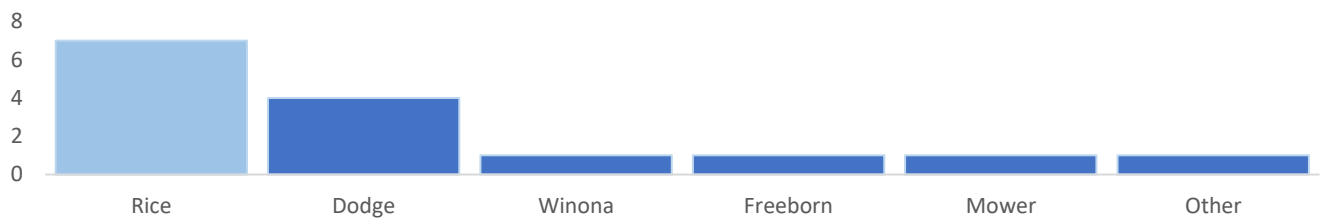


Figure 5: Participating Counties in Focus Group and Interviews



The following findings have been grouped into the four main objectives that were investigated during the focus group and individual in-depth interviews.

Objective 1: Definition and Community Perceptions

Participants defined disabilities as an impediment limiting aspects of their lives.

Participants in the focus group and the interviews alike had not heard many words used to describe disabilities, some have heard or seen the words *“discapacidad”* (disability), and *“incapacitado”* (incapacitated). One participant said they have heard the term *“imposibilitados”* (person is unable) in their home country of Mexico. Some also stated that they have heard or seen terms used specific to a disability, for example, paralyzed, blind, deaf, etc. Participants defined a disability as an impediment that limits many aspects of their lives or the lives of people they know. Others did not know how to clearly define a disability, but they saw it as “lacking” something in life.

“They’re just not people, they’re not whole people. I imagine they’re missing something.”

For some, it affects their ability to complete daily activities and sometimes requires the assistance of someone else. One participant defined disability as *“something that prevents you from carrying out either work or daily activities, which for others are a simple routine.”* Most participants also distinguished between mental and

⁵ For both focus group and interviews, the participants self-reported on the disabilities encountered. Those that selected “other,” were prompted to specify.

physical disabilities. Participants shared that mental disabilities are not always visible and acknowledged by others if they do not appear severe. Similarly, a participant defined disability as a spectrum, where the levels of impediment vary between cases.

Participants described instances in which their community members have made hurtful comments.

When discussing the general views that the Latine community has on disability, many participants who self-identified as having a disability said they experienced **hurtful comments** from other community members. Nicknames are sometimes made to those with a disability that are intentionally or unintentionally harmful. A participant stated these nicknames and hurtful comments usually come from people who may not have had much access to education or experience with people who have disabilities.

A participant shared words they've heard when talking about someone with a disability, such as **"invalid, blind, deaf, dumb, or stupid."** Another participant shared that while they often heard the word **"special"** being used by other community members, as a person with a disability, they didn't appreciate being referred to that way. Some have experienced others **laughing** at them when they walk by. In addition to hurtful comments, some participants shared feelings of **isolation** and **ostracization** within their community.

"It feels like they're in a separate world."

A participant shared that they were told that they do not have a disability based on the community's perceptions of what someone with a disability should be able to do or not do. She stated that she felt that she had to constantly **prove** that she had a disability and explain why she did things in a certain way. In the same breath, the Latine community highly regards **perseverance** and does not view members as having a disability if they are **high functioning**, such as holding a job or attending school. A participant said that community members think **"they are doing it on purpose."** Another participant felt as though she needed to exaggerate her condition for others to believe them and receive support.

Although some participants believed that the community has been improving in the recent years and become more tolerant of different disabilities, they agreed that there is room for **improvement** in educating Latines on how to best support and understand people with disabilities in their community.

Objective 2: Experiences, Challenges and Barriers

Participants described their experience with having a disability as having a great impact on their life.

Participants in both the focus group and interviews varied in their disabilities. Some were parents to children born with a disability, others experienced a disability later in their life due to an accident, health condition, or violence. All participants described their experiences with a disability or caring for someone with a disability as **impactful, a big shift in their life**. Many also admitted that they were not equipped with the necessary knowledge, emotional tools and resources to face such a challenge.

Another participant described her experience of having a child with a disability as a time of uncertainty since, *“I didn’t know he was going to be born with a disability, and I didn’t really know if he was going to walk or talk at all.”* Parents of a child with a disability have described their experience as difficult, especially having more than one child, but it has been a learning experience and a life they have adapted to with the support of other family members.

Participants also shared the impact a disability has on their mental health. Many share feelings of **depression, helplessness, shame, and embarrassment**. One participant shared, *“I am with the depression of not being able to do things on my own.”* A participant said they felt, *“embarrassed, you feel like you can’t. It’s not easy to handle these things.”* Another participant shared that they felt they were missing out on important life events, like the birth of their granddaughter. She said that she felt sad because once her granddaughter is born, she will not be able to see her face due to her vision worsening.

These negative feelings also stem from the **inability to live independently** and having to rely on others. This is especially present when wanting to do personal activities, such as bathing and eating. A participant shared these feelings of helplessness in regard to her daughter taking care of her, *“I am very helpless because I can’t help her, because I can’t help myself.”* Another participant shared that when he takes care of his grandfather, he has to wait for him outside of the restroom because his grandfather does not like being helped while he uses the restroom as it makes him feel useless, but he needs to be kept an eye on, so he does not fall or get hurt.

The emotional and physical toll on caregivers was also mentioned as part of the challenge to support a loved one with a disability.

Another participant shared the impact they felt seeing her brother **decline in health and ability**. She described him as *“an excellent man, hard-working, responsible, magnificent,”* but his stroke caused him to be partially paralyzed and worsened his dementia. She saw him become more dependent on others and *“out of control.”* He would wake up upset or confused and would begin to talk about the past as if it were the present. She said that *“one wants him to be the same and sometimes we don’t understand him.”* Nonetheless, she continued to help him with his daily activities, like feeding and bathing him.

Participants experienced barriers due to their legal status and language needs.

In addition to the emotional and physical barriers experienced by individuals with disabilities and their caretakers, there are more challenges added to the community if they **do not have legal status or speak English**. Participants discussed immigration status as a **constant challenge** when looking for resources and support, especially help provided by the state and county.

“If you don't have papers, the government doesn't recognize you, and there's no one who will do anything for you. If you're not legally allowed to be here, you can go around shouting that you suffer from a disability. And who's going to care?”

A participant shared her personal experience with discrimination as a Latina with a disability living in an apartment designated for those with disabilities. Other tenants have **sexually harassed** her and when she rejected their

advances, they **attempted to report her to immigration**. She did not even feel safe in the housing that was meant to help take care of her.

“How am I going to go find support when they are threatening me with deportation?”

In addition to immigration status, participants expressed the importance of having someone who speaks Spanish present in **translating important information**. Some participants shared their child’s role in translating for them, but sometimes it is not reliable because they do not have the patience or have other responsibilities to attend to. Participants that do not have a family member to translate for them are left without access to information and resources due to not being able to understand and communicate in their native language. A participant mentioned this challenge being worse as she is hard of hearing and already **struggles to communicate with others**. This is especially important when discussing health concerns and needs. There is a necessity to communicate clearly to not only receive support, but to follow up on it.

The list of challenges experienced also extended to **financial concerns**. A participant shared that there is more to caretaking than making sure the other person eats and sleeps, but **“sometimes you have to survive,”** and focus on how to financially take care of them. Many participants shared their concern about being the primary caregiver because of the financial burden they experience. A participant with a disability had to take a taxi three times a week to the clinic, which her daughter had to pay for. All she could feel was guilt for being a financial burden to her daughter, but the constant visits to the clinic were crucial in improving her quality of life.

Objective 3: Existing Support and Needs

Participants receive their primary support from family and community members.

As seen throughout the focus group and the interviews, family is essential in providing care and support.

“I believe it is something familial, right? When there's someone with a disability in a household, it doesn't just involve the parents anymore; it involves the siblings, probably the aunts and uncles, the cousins.”

Participants shared instances in which they received support from their family members with their daily activities or moments when they had to support their family members with a disability. A participant shared how the responsibility of being the primary caretaker was so exhausting that she had to take turns with her siblings to take care of their relative. Another participant shared that his cousins also help take care of their grandfather because they all have to work and cannot be with him all the time.

Through the toughest times, family plays an important role in supporting people with disabilities, but their knowledge is limited. Community members and organizations fill in the gap where families are not able to support.

At the time of the discovery of a disability or the diagnosis, participants shared that there was a main person of contact in their community that provides them with resources and information. These people are either doctors,

community health workers, interpreters, school social workers, teachers, or therapists. Whenever participants have questions or need additional resources, they go to their main person of contact for support. Having a **trusted person** of contact has been **very helpful** to many participants as many did not know where to even begin to search for help. This is especially true when the person of contact holds a “**privilege**” based on their role in the community or social status.

Participants shared many current services they used (see Table 1) but some said that it was very surface-level assistance. The services used are not long-term or do not provide a follow-up to certain conditions, especially if you do not have access to health insurance or other financial assistance. This is important because some said they do not seek medical services or treatment due to costs or access.

Table 1: Current Services Used
<ul style="list-style-type: none">•At-home nurse•Community clinics<ul style="list-style-type: none">•Mental health therapy•State and county services<ul style="list-style-type: none">•Financial help, WIC, SNAP•Health insurance•Spanish-speaking nonprofits•School services<ul style="list-style-type: none">•Speech and behavioral therapy

Participants have many needs and require access to services to better achieve an independent life.

Many participants shared the challenges of being financially responsible for their services or the services received by their family members. Caretakers usually dedicate most of their time to taking care of someone with a disability, even having to leave their employment. Many participants shared that one partner is the breadwinner of their family so their spouse can take care of their child with a disability full-time. This makes it a challenge to be able to afford extra support and resources from childhood to adulthood.

Doctor visits and prescribed medication or equipment are not as accessible when they are not **free** or **low-cost**, causing many to not receive the adequate medication to improve their quality of life. Another participant stated that she was not able to afford a hearing aid, but a community member from her church gave her one. Unfortunately, her toddler broke the device, and she was not able to afford a replacement.

“And most of all, they had to prescribe me the lowest-cost insulin because the one I was using was too expensive, and I couldn't afford it anymore. That's when my vision deteriorated the most because this insulin helps me, but not like the other one that's so expensive. And I can't buy it because there's no money.”

Some participants shared that the school has had a large role in providing speech and behavioral therapy to children with disabilities, but one parent stated that once the child got older the school mainly worked alongside the student and the parent was no longer as engaged as she hoped in her child's learning. Parents also expressed the need for **childcare** specific to children with disabilities. The primary caretaker, typically the mother, is in charge of caring for

the child 24 hours a day. Some expressed it would be helpful to have a **free** or **low-cost daycare program** available for a few hours to be able to have some time to take care of other household matters or just to have some personal time alone. Having a childcare service specific to children with disabilities is also another way to help the child socialize and create connections.

Participants listed other services needed, such as **assistance finding employment** that matches their abilities, **food assistance**, **health insurance**, **transportation**, **sign language classes**, and other forms of **behavioral therapies**. A lot of these services have not been accessed by the participants due to **financial hardship**, **lack of information**, **language and communication barriers**, and **immigration status**. In addition to these needs, other participants said they would really benefit from events or programs that are specifically meant for people with disabilities or caretakers and parents of people with disabilities so that they are all able to interact with people with similar experiences and **learn from each other**.

Objective 4: Engagement Strategies and Promotional Services

Participants value trust and prefer organizations that share similar language and culture. Trust was a common theme discussed in the focus group and the interviews alike when asked about how an organization can reach the Latine community. Most agreed that trust is important when addressing feelings of shame and embarrassment.

“Well, I wanted to mention that there are people who feel ashamed to talk, feel embarrassed to express their feelings, and feel embarrassed to seek help. Sometimes we lack the confidence to feel secure enough to talk to someone.”

In order to **build trust** with the Latine community, organizations and services need to be **available in Spanish and culturally relevant**. Participants discussed the significant difference between having just translators available and having staff members that are Latine. They prefer to have staff members who speak and know the culture, that way nothing is lost in translation.

A participant also shared that having services available to people **without legal documentation** should be a priority for community organizations, especially when looking for funds. Many participants shared that their immigration status has prevented them from seeking help because they are **afraid** of outing themselves.

Many barriers already exist that prevent the Latine community with disabilities from receiving assistance and this becomes more of a challenge when there is no trust and respect.

A participant shared her experience working at a school in which she had to do a home visit for a family whose children were not attending school. When completing the home visit, she had learned that the mother had gone to the school and asked for help, but **“they humiliated her. So, the mother lost her trust, and when the mother lost her trust, her children lost their trust as well, to the point that they no longer attended [school].”** This is especially true when it comes to families who do not want others to know about their family’s disabilities or their own. They do not want to be in a more vulnerable situation.

There has been **positive feedback** in the focus group and the interviews in which participants were **comfortable** sharing their personal experiences and appreciated the time spent on getting to know more about their challenges and needs. A participant struggled to join the video call meeting to participate in the individual interview and after half an hour she was finally able to log in. During the interview she expressed her appreciation for helping her join the meeting and for having patience with her, she said *“it shows your interest, and that's what really matters.”* Knowing that the person you are speaking to is not going to judge and is there to help creates comfort and trust in the organization and their staff. Although, as stated by a participant, it can sometimes be difficult for Latines to get out of their comfort zone and routine to search for assistance.

“Indeed, there are many organizations with many initiatives and events for the benefit of the Latino community. However, many of us Latinos also don't take advantage of these resources or rather, don't consider them, because we live in a very routine life. We focus on our jobs, our families, and our homes, and at a certain point, we might not want to go out or dedicate time to learning or exploring other things.”

Many participants said they prefer organizations to come to them and make themselves known, instead of the Latine community having to find them. Participants have shared throughout the conversations that they are not aware of organizations and resources available to them. Without knowing about the existing help, they will not be able to reach out for assistance.

Participants seek resources and information online and through word of mouth.

Almost all participants said that they receive their information from social media, especially Facebook. Once someone shares a post with information or an event, others begin to share it and, as one participant described, it becomes **a chain reaction**. This also happens with word of mouth. Once someone discovers an organization or service that is free or low-cost, they will share it with other community members **by word of mouth**.

Participants also preferred to receive their information from their **local churches, cultural supermarkets, Walmart**, and from their children's **schools**. Participants also preferred the information to be shared in a more intentional manner.

“Taking it beyond just putting up a sign on your door and relying on word of mouth from neighbors, actively spreading information about the services you offer. You could consider organizing resource fairs where various institutions and organizers come together to showcase available resources for the community. Making it an open event can help raise awareness about the services.”

During the conversations with the participants, they also suggested that SEMCIL connect with other existing nonprofits and community clinics that are connected to the Latine community.

Even just connecting with a local community leader can help disseminate promotional material more effectively. Again, once that trust has been established, the community's trusted leader will share the information with those

that seek help. Participants also preferred community engagement through **support groups** for people with disabilities and caretakers, **workshops**, **informational sessions**, and **conversations** with SEMCIL. A participant shared that he did not know many parents with children who have disabilities. He would like to be able to meet others with similar experiences to be able to share resources and support with each other.

Discussion

The findings of this research project align with existing literature, shedding light on the unique challenges and barriers faced by the Latine community with disabilities in Southeastern Minnesota.

Previous studies show that the values of the Latine immigrant community ties perseverance and productivity with feelings of self-worth, such as independence, freedom, recognition, and power (Hernandez-Wolfe, 2022). These values were also prevalent among this study's focus group and personal interview participants. Their frustration with having their disability dismissed or not taken seriously enough to receive support if they were high-functioning individuals or their disability wasn't visible created feelings of shame and distrust. On the other hand, when an individual's disability prevented them from completing their daily tasks and being independent, they were not seen as a whole person. Therefore, those with disabilities have their worth questioned frequently causing feelings of helplessness and embarrassment. This perception of disability also creates cultural stigmas.

Stigmas in the Latine community stem from different cultural elements, including the "collectivistic" characteristic of the culture in which the perception and inclusion from other community members is significant (Abdul-Chani, Moreno, Reeder, Zuckerman, & Lindly, 2021). Because of this, in the U.S., stigma towards disability is more prevalent among Latines with lower levels of acculturation. This aligns with what the participants in our study shared about not being treated as a whole person, especially by people with low education and knowledge. Hurtful comments stem from existing stigmas in the community and the lack of understanding and information on disabilities.

In contrast to other populations, the Latine community in the U.S. is more likely to face challenges and barriers concerning "language, discrimination, economic status/finances, and immigration status, all of which contribute to poor access to health services" (Balcazar, Magaña, & Suarez-Balcazar, 2019). Due to their lack of access to health care, many resort to receiving support from their family and trusted community members. The Latine community often views disability as a family responsibility rather than an individual matter. Because of the cultural value of familism, many Latine individuals with disabilities live at home and rely on social and caregiving support from their family (Balcazar, Magaña, & Suarez-Balcazar, 2019). However, this protective support can create a very significant caregiving role, particularly for women in the household. Mothers of children with disabilities, for example, face challenges as they do not have breaks or time for themselves and the necessary support, putting their own wellbeing and health at risk (Magaña & Smith, 2008). Similar sentiments were shared in this study, where caregivers shared feelings of mental and physical fatigue.

This is significant because, despite the social and structural challenges, the collective nature of the Latine culture creates a collaborative process in which individuals who share similar challenges and barriers can come together to support each other in addressing their shared needs (Balcazar, Keys, & Suarez-Balcazar, 2001). If there are trusted community members or organizations, information and resources can be quickly distributed to address the current barriers.

Overall, the results of this study correlate with the existing discourse on the unique experiences of other Latine communities with disabilities in the U.S. These specific needs and barriers reveal the complex interaction between

cultural values, social dynamics, and structural discrimination that affect their daily lives and access to necessary services for a more independent life.

Limitations

It is important to acknowledge that a small sample of the Latine population either living with a disability or connected to someone with a disability participated in this study. While the sentiment expressed by the participants cannot be generalized to the Latine population in Southeastern Minnesota living with a disability, these conversations created significant insights into designing services that are more culturally centered and provide better support for this specific community.

In addition, our study did not obtain participation and representation from all Southeastern counties. This was due to the narrow eligibility requirements needed to participate, such as identifying as Latine or Hispanic, having a disability or knowing someone with one, and living in the eleven Southeastern counties. Almost half of the total participants were from Rice County. Rice was the only county where HACER could participate in an in-person community resource fair. Unfortunately, there were no similar opportunities in the remaining Southeastern counties.

Lastly, despite increasing outreach efforts, participant turnout was not as expected. Outreach for focus groups consisted of contacting local schools, nonprofits, libraries, clinics, as well as attending the in-person community resource fair in Rice County. Seeing the low registration rate and recognizing the sensitive nature of the conversation and its potential discomfort in a group setting, we opted for individual in-depth interviews to establish a secure environment for participants to share their personal experiences. This approach not only ensured a safer space for conversation but also attracted more participants who might have been initially hesitant to engage in a traditional focus group.

Conclusion

This study provides valuable insights into the complex challenges and barriers experienced by the Latine community when navigating disabilities, whether it involves the individual with a disability or those who provide support. Among the notable challenges are language barriers that prevent proper communication, community misconceptions that perpetuate stigma, and a widespread lack of awareness about available resources and help. By discussing these issues, this research highlights the importance of intentional intervention and support systems that can alleviate these barriers and promote the inclusivity and wellbeing of the Latine community with disabilities in Southeastern Minnesota. The following are recommendations to help address these challenges and barriers.

Recommendations

1. Creating and disseminating culturally relevant outreach and educational material.

It is important to create outreach and educational material in Spanish to share the available services with the Latine community with disabilities with culturally relevant language that reflect the community's values, norms, and lived experiences. The information can be disseminated online through social media, TV and radio stations, physical flyers and brochures, and through in-person outreach. This will ensure that individuals feel understood and can trust that the services will help them, breaking down language and information barriers.

2. Strengthening community connections and partnering with local leaders and organizations.

Participants in this study shared instances in which a community leader or trusted person of contact was able to support them and advocate for their needs. Partnering with already established collaborative work within the community can help build trust and address service needs.

3. Personalizing care and services to cultural-specific needs.

When personalizing care and services to the Latine community with disabilities, it is important to understand cultural nuances and beliefs. This can be accomplished by employing culturally competent staff, including members of the Latine community, and/or developing workshops and training to take part in a more intentional interaction with the community that resonates with their values. Ideally, involving community members in the planning and development of care and services can ensure that dignity and respect is upheld.

4. Assess the effectiveness of implemented initiatives through conversation with the community.

Regularly scheduled feedback sessions, focus groups, interviews, and surveys can provide important insight into the effectiveness of the services. Not only will these conversations help improve the services provided, but it will also reinforce the partnership and trust with the Latine community with disabilities in Southeastern Minnesota.

Bibliography

- Abdul-Chani, M. M., Moreno, C. P., Reeder, J. A., Zuckerman, K. E., & Lindly, O. J. (2021). Perceived community disability stigma in multicultural, low-income populations: Measure development and validation. *Research in Developmental Disabilities*.
- Balcazar, F. E., Keys, C. B., & Suarez-Balcazar, Y. (2001). Empowering Latinos with Disabilities to Address Issues of Independent Living and Disability Rights: A Capacity-Building Approach. *Journal of Prevention & Intervention in the Community*, 1-112.
- Balcazar, F. E., Magaña, S., & Suarez-Balcazar, Y. (2019). Disability Among the Latinx Population: Epidemiology and Empowerment Interventions. *New and Emerging Issues in Latinx Health*, 127-143.
- Hernandez-Wolfe, P. (2022). Nepantla Moments in Therapy: A Clinical Example with Latinx Immigrants. *Women & Therapy*, 157-174.
- Indiana University. (n.d.). *Understanding Accessibility*. Retrieved from Indiana University: <https://accessibility.iu.edu/understanding-accessibility/types-of-disabilities.html#neuro>
- Magaña, S., & Smith, M. J. (2008). Health behaviors, service utilization, and access to care among older mothers of color who have children with developmental disabilities. *Intellectual and developmental disabilities*, 267-280.
- Minnesota Compass. (2021). *By Disability*. Retrieved from Minnesota Compass: <https://www.mncompass.org/chart/b14685-1/disability#print>
- U.S. Census Bureau. (2017-2021). *Age by Disability Status (Hispanic or Latino) American Community Survey 5-year Estimates*. Retrieved from https://censusreporter.org/data/table/?table=B18101I&geo_ids=04000US27,050|04000US27&primary_geo_id=04000US27
- Vanek Smith, S., & Garcia, C. (2020, June 8). *The Minnesota Paradox*. Retrieved from NPR News: <https://www.npr.org/2020/06/08/872639451/the-minnesota-paradox>

Appendices

Appendix 1: Focus group protocol

SEMCIL Focus Group

Facilitator:

Notetaker:

Date:

Introduction

Facilitator: Hello everyone and thank you for coming today. My name is Monica Yanez, and I am a Research Associate at HACER. I will be leading this conversation today and will be asking questions to learn more about your attitude and definition of disability, as well as experiences with having a disability or caring for someone with disabilities to understand possible challenges within the community.

On this call, we also have **NOTETAKER** who is going to be our notetaker with us today to assist me and take notes during our discussion. I appreciate all of you taking the time to be here today and for your willingness to share your experiences. Our hope is that by the end of this conversation, we will develop a clearer idea of your experiences as a person with disabilities or as someone who cares for a person with disabilities. These questions will highlight your perception and definition of disability, access needs, experience living with a disability or with someone who has a disability, and possible challenges. Your insights and recommendations will help Southeastern Minnesota Center for Independent Living, or SEMCIL, to develop plans to partner with the Latine community in southeastern Minnesota to address possible needs and provide support. Serving southeastern Minnesota since 1981, SEMCIL is an organization of people with disabilities who partner with individuals to understand their needs, explore options, and develop goals. SEMCIL staff value the dignity and wellness of every person. SEMCIL services are available to anyone of any age who self-identifies as having a disability. There is no cost for SEMCIL services, and they do not require medical documentation. SEMCIL can help you increase access to your community, explore ways in which you can increase your independence at home, and much more. You work with SEMCIL to set your goal(s) your way - this is the basis of all SEMCIL services- by people with disabilities for people with disabilities.

While I will be asking questions today to address these topics during our time together, I would like this to be an open conversation. This is a safe space where there are no right or wrong answers. My only goal is to understand your experiences and needs, so all information, all opinions, all questions and so on are valuable and valid. Feel free to talk amongst each other and follow up on others' points, however, please do be respectful of everyone's point of view. If the conversation deviates too far off track, I may step in to get us back on track. Lastly, if we are spending too much time on one question, I may interrupt to make sure that your voices are heard for all questions we have prepared today. Also, feel free to use the chat feature on Zoom to answer.

I would also like to inform you that this conversation will be recorded for notetaking purposes. While **NOTETAKER** does a great job of taking notes, they are not able to get all the details in real time. Recording helps us ensure that we get the best details and that we accurately understand and report what you share. I can promise you that no names will be used in any final reporting or shared by myself or the notetaker outside this conversation. Your identities are confidential. I ask that you all do the same; whatever is mentioned during this conversation should stay within this room and no names or identifying information should be repeated. To preserve that anonymity, you may also keep your camera turned off during the session if you would like and you may also change your

screen name to something different, such as “Participant 5”. Lastly, this recording will be saved on a password protected computer and will only be shared with the researchers working on this project at HACER. Information gathered in this project will also be visible to the client who would like this information collected: SEMCIL. If anyone does not feel comfortable with us recording this session, we will make do with the notes that we are able to take. This will not in any way affect your relationship with any organization involved in this project or any of its members.

As we get ready to start, I ask that you please mute yourselves if you are not already. If you need to take a step out to make a call, to use the restroom, or to address something at home, that is totally fine. As I mentioned, this is just a conversation, so please make yourselves comfortable.

I will give everyone a second to mute their mics or to turn off your cameras or change your names if you would like. I will begin recording now.

Questions

1. I would like to start off with some introductions.
 - a. If you could each, please introduce yourselves, I will pick based on how you appear on my Zoom screen. **Please start by saying your name, and what you are most excited for the Spring.**
 - i. I can start and I’ll reintroduce myself. My name is Monica Yanez, and I am most excited for...
2. How would you define disability?
 - a. *Probe:* What does disability mean to you?
 - b. *Probe:* What would you classify as a disability?
3. What other words have you heard or seen used to describe disability?
 - a. *Probe:* Is there a word that would be better used than disability?
4. How do you think the Latine/Hispanic community in general views disability?
 - a. *Probe:* Does the Latine/Hispanic community define disability differently than your own definition?
 - b. *Probe:* How have you heard others talk about it? Has it been positive or negative?
5. What is your experience with disability?
 - a. *Probe:* How has your experience impacted your life?
 - b. *Probe:* How has it impacted someone you know that has a disability?
6. In your experience, what are some factors that make it harder for people with disabilities to complete their daily activities by themselves?
 - a. *Probe:* Are there certain conditions that do not allow certain individuals to live independently?
7. What services do you or someone you know who identifies as having a disability need?
 - a. *Probe:* Food, education, transportation, finance, others?
8. What has made it **easier** to get the services you or someone you know who identifies as having a disability need?
 - a. *Probe:* Family member, friend, community organization, online.

9. What has made it **harder** to get the services you or someone you know who identifies as having a disability need?
 - a. *Probe:* Cost, stigma, language, limited access to information or resources.

10. What kind of support are you currently receiving to help you complete your daily activities?
 - a. If yes, how was the experience?
 - b. If no, what prevented you or someone you know from receiving assistance or support?

11. What ways can an organization reach the Latine/Hispanic community and share the services they provide?
 - a. *Probe:* Where should they share information?

12. Is there anything you think SEMCIL should know about your culture or community, that would help them address possible needs and promote their services?
 - a. *Probe:* about the community's values, family dynamics, how they communicate, or anything else?
 - b. What could an organization do to build trust within the Latine/Hispanic community?

13. Is there anything else that you think SEMCIL should think about when reaching out to the Latine/Hispanic community to inform the community about their services?

Thank you for your participation in this conversation, we are glad to hear your perspective and your experiences. If you have any questions after this meeting, you are more than welcome to call, text or email me. I will add my information in the chat as well as in the follow up email I will send with SEMCIL's contact information and resources. Additionally, if you know other people that may be interested in participating in this project, feel free to give them my contact information. You will be receiving your [incentive details].

Appendix 2: In-depth interview protocol

SEMCIL Interview

Facilitator:

Notetaker:

Date:

Introduction

Facilitator: Hi, just to introduce myself, my name is Monica Yanez, and I am a Research Associate at HACER. I will be conducting this interview today and will be asking questions to learn more about your attitude and definition of disability, as well as experiences with having a disability *or* caring for someone with disabilities to understand possible challenges within the community.

On this call, we also have **NOTETAKER** who is going to be our notetaker with us today to assist me and take notes during our discussion. I appreciate you taking the time to be here today and for your willingness to share your experiences. Our hope is that by the end of this conversation, we will develop a clearer idea of your experiences

as a person with disabilities *or* as someone who cares for a person with disabilities. These questions will highlight your perception and definition of disability, access needs, experience living with a disability or with someone who has a disability, and possible challenges. Your insights and recommendations will help Southeastern Minnesota Center for Independent Living, or SEMCIL, to develop plans to partner with the Latine community in southeastern Minnesota to address possible needs and provide support. Serving southeastern Minnesota since 1981, SEMCIL is an organization of people with disabilities who partner with individuals to understand their needs, explore options, and develop goals. SEMCIL staff value the dignity and wellness of every person. SEMCIL services are available to anyone of any age who self-identifies as having a disability. There is no cost for SEMCIL services, and they do not require medical documentation. SEMCIL can help you increase access to your community, explore ways in which you can increase your independence at home, and much more. You work with SEMCIL to set your goal(s) your way - this is the basis of all SEMCIL services- by people with disabilities for people with disabilities.

I would also like to inform you that this conversation will be recorded for notetaking purposes. While **NOTETAKER** does a great job of taking notes, they are not able to get all the details in real time. Recording helps us ensure that we get the best details and that we accurately understand and report what you share. I can promise you that no names will be used in any final reporting or shared by myself or the notetaker outside this conversation. Your identity is confidential. Lastly, this recording will be saved on a password protected computer and will only be shared with the researchers working on this project at HACER. Information gathered in this project will also be visible to the client who would like this information collected: SEMCIL. If you do not feel comfortable with us recording this session, we will make do with the notes that we are able to take, just let me know. This will not in any way affect your relationship with any organization involved in this project or any of its members.

Any questions before we start? I will begin recording now.

Questions

1. How would you define disability?
 - a. *Probe:* What does disability mean to you?
 - b. *Probe:* What would you classify as a disability?
2. What other words have you heard or seen used to describe disability?
 - a. *Probe:* Is there a word that would be better used than disability?
3. How do you think the Latine/Hispanic community in general views disability?
 - a. *Probe:* Does the Latine/Hispanic community define disability differently than your own definition?
 - b. *Probe:* How have you heard others talk about it? Has it been positive or negative?
4. What is your experience with disability?
 - a. *Probe:* How has your experience impacted your life?
 - b. *Probe:* How has it impacted someone you know that has a disability?
5. In your experience, what are some factors that make it harder for people with disabilities to complete their daily activities by themselves?
 - a. *Probe:* Are there certain conditions that do not allow certain individuals to live independently?
6. What services do you or someone you know who identifies as having a disability need?

- a. *Probe:* Food, education, transportation, finance, others?
7. What has made it **easier** to get the services you or someone you know who identifies as having a disability need?
 - a. *Probe:* Family member, friend, community organization, online.
8. What has made it **harder** to get the services you or someone you know who identifies as having a disability need?
 - a. *Probe:* Cost, stigma, language, limited access to information or resources.
9. What kind of support are you currently receiving to help you complete your daily activities?
 - a. If yes, how was the experience?
 - b. If no, what prevented you or someone you know from receiving assistance or support?
10. What ways can an organization reach the Latine/Hispanic community and share the services they provide?
 - a. *Probe:* Where should they share information?
11. Is there anything you think SEMCIL should know about your culture or community, that would help them address possible needs and promote their services?
 - a. *Probe:* about the community's values, family dynamics, how they communicate, or anything else?
 - b. What could an organization do to build trust within the Latine/Hispanic community?
12. Is there anything else that you think SEMCIL should think about when reaching out to the Latine/Hispanic community to inform the community about their services?

Thank you for your participation in this conversation, we are glad to hear your perspective and your experiences. If you have any questions after this meeting, you are more than welcome to call, text or email me. You will receive a follow up email with SEMCIL's contact information and resources. Additionally, if you know other people that may be interested in participating in this project, feel free to give them my contact information. You will be receiving your [incentive details].

Appendix 3: Participant quotes

Objective 1: Definition and Community Perceptions

“Disability, in my opinion, is like in levels. There are people who face obstacles that make it very difficult for them to live their lives on a daily basis. And there are other people who may face a part of their disability, but there they do it, there they try to overcome things and it makes them difficult, but it does not prevent them from feeling successful in moving forward.”

“They see me as very highly functioning. And they think, ‘no, but where? It’s just that I don’t see the disability, you’re fine. I judge that you are fine.’ Why? Because she went to law school, because she survived life and she is a fighter. ‘Well, make the fight, you’re fine.’ I have been told by so many, many people that even I have been made to feel that I have to exaggerate. But I’m not exaggerating. But I know that it seems to them that you are exaggerating to make them understand that you are really suffering inside, even if you are invisible to them. That same theme, invisible. My disability is invisible, so they don’t believe me.”

Objective 2: Experiences, Challenges and Barriers

“So, when a person with a disability enters your life, I mean, it’s an impact. You don’t know how to handle it because you don’t have the education and knowledge to do it and honestly, well no one tells you, ‘hey, well there are resources, there is another way, you can go to such place.’ That is to say, we are very limited.”

“It is not only from the person who has the disability, but also from the family and the one who takes care of the person, because you are not only taking on a disability in yourself, but for us, for caregivers, it is also a mental and physical fatigue.”

“So, yes, it is a bit more difficult, because if there are many of us who can understand [English] but can't speak it, then it is challenging for us, like asking a question about what's going to happen or what will come next.”

“When I had the car accident, I was paralyzed from my neck down. I couldn't move anything except my eyes, and gradually, by the grace of God and through my own efforts, attending therapy, getting massages, trying different things, and with the support of various organizations and doctors, I couldn't do it alone. Not just me, but my family as well, they were there, but even they struggled because they didn't know how to help me. But my disability has helped me in a way, because now I know that I not only have a family supporting me, but also other people in the community who are supporting me.”

Objective 3: Existing Support and Needs

“She lent me her privilege to help me get in there. If I couldn't access the privilege of the Americans, if I wasn't aware of that and I wasn't aware of how to use that privilege to help me get in, I wouldn't have been able to. That's the key to how they can help, then.”

“Sometimes we are thankful for these free clinical institutions, but at times the services they provide are for basic illnesses and they cannot provide ongoing care for a more serious condition.”

“Where he could interact with more people who are like him, who have disabilities, right? Because it would be an easier way for him, as sometimes he doesn't want to go out, doesn't want to go anywhere, because he doesn't have the ability to communicate, to socialize, he feels limited as well. Seeing people like him, I think it might help him a bit to come out.”

Objective 4: Engagement Strategies and Promotional Services

“Just imagine the barriers this person will face when someone makes fun of them, especially in a place they thought was safe, where they could go to express their needs. Not only will they face the language barrier, but also distrust and ridicule. On the contrary, instead of creating a welcoming environment for the person, you're going to make them not want to come back anymore.”

“Well, I imagine it must be even more complicated for many because they might think they'll be judged or criticized. They may fear that their family, their children, or themselves with a disability will be criticized. It's like exposing them, making them known to people, because there are many individuals with disabilities, and others might not be aware of it.”

“I believe it's always good to go out into the community. Don't wait for people to come to the service. The service should reach out to the community and say, "These are available," so that people not only know about the resources but also see the individuals working within the organization. This helps them become more familiar with it.”

“Your voice is, well, the voice, it travels. Words fly, they pass from one to another. Speaking is like planting a seed that will grow, because not everyone sees Facebook or is online.”

“Connect with existing groups in the community that are already doing this type of work, like grassroots workers and nonprofits such as Health Finder clinics. The people working there are individuals who understand the culture, know the language, are familiar with the community, and already have connections within the community.”