



Semi-structured interviews on disaster and emergency preparedness for people with disabilities in two states in Mexico

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Abstract

When a disaster occurs, people with disabilities are at a higher risk to adverse health outcomes due to inadequate access to resources, high levels of exposure to hazards, and an overall lack of integration with emergency responders. The purpose of this qualitative study was to explore and describe perspectives of people with disabilities (PWD) in the context of emergency and disaster preparedness in Mexico. The Bronfenbrenner's bioecological systems theory and the social model of disability were utilized to frame this study. Utilization of standpoint epistemology and community-based input from the focus population allowed for greater understanding of their needs and revealed the potential steps toward promotion of disaster and emergency preparedness among these vulnerable communities. Six surveys were completed by rehabilitation professionals all over Mexico, and eleven semi-structured interviews were completed with PWD in two different research settings in Mexico. The findings provide a precise and nuanced understanding of holistic inclusion in disaster and emergency situations. This study uncovers many unmet needs in the community and input on how to address these issues through grassroots coalition building and inclusion. This study reflects the same urgency as seen in the 2018 Intergovernmental Panel on Climate Change (IPCC) Report; however, in this study, this assertion is conveyed through the perspective of those who have lived through disastrous events in Mexico in recent years. Conclusively, promotion of emergency and disaster preparedness among people with disabilities will only be achieved through an intersectional and inclusive, equity-based approach to human rights.

Keywords Disaster preparedness · Emergency · Risk reduction · Health promotion · Disability · Mobility disability · Visual disability

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1 Introduction

The World Health Organization and the World Bank estimate over one billion people experience disability around the world. Within this group, 100 million have a disability relating to mobility and function, and of these less than 20% have access to an appropriate wheelchair or assistive device (Armstrong et al. 2008; World Health Organization [WHO] 2011). Despite these staggering numbers, few community-based plans have been developed in regards to climate related disasters and emergencies (Cruz-Vega et al. 2016; Dora and Hiram 2019; The Global Partnership for Disability and Development 2009; Malpass et al. 2019; Wolbring and Leopatra 2012; World Health Organization 2011).

According to the 2018 Intergovernmental Panel on Climate Change (IPCC) Report, extreme weather events and disasters are projected to increase “in frequency and severity” if global warming continues at its current rate, reaching 1.5 °C above pre-industrial levels (Allen et al. 2018). In consideration of vulnerable populations such as people with disabilities (PWD), an increase in extreme weather events will necessitate a dynamic cross-agency intersectional approach. Unfortunately, there is a significant disconnect between disability organizations, the public health sector, and disaster risk reduction agencies. This disconnect, and the subsequent lack of published literature on this topic, results in a lack of cohesive response to disasters and emergencies among some of the most marginalized populations (Grech 2015; Lunga et al. 2019; Priestley and Hemingway 2006). PWD are poorly supported in climate adaptation and mitigation, ultimately assuring adverse health outcomes for PWD in the face of disasters (The Global Partnership for Disability and Development 2009; Levac et al. 2012; Lippmann 2011; Wolbring 2009; Zedillo Ortega and Gomez Bruera 2018). The 2018 Executive Summary of the Disability and Development Report suggests 72% of persons with disabilities have no personal preparedness plan for disasters and 79% would not be able to evacuate immediately without difficulty (United Nations 2018).

Current phenomenological literature regarding the lived reality of PWD in disaster and emergency scenarios is extremely limited and insufficient. PWD are rarely engaged in a research setting or when community input is gathered regarding emergency and disaster preparedness. Lack of attention to this issue leaves communities seldom knowing where PWD reside in their respective communities, and thus, PWD are isolated from assistance and access to the appropriate resources (Smith and Notaro 2015; Wolbring 2009). However, the limited published research that does exist, strongly suggests that inclusive direct stakeholder needs assessments are critical and that these assessments need to involve the population in question as an integral part of that process (Aryankhesal et al. 2018; Gil-Rivas and Kilmer 2016; Hidayati 2012; Levac et al. 2012; Lippmann 2011; Malpass et al. 2019; Rooney and White 2007; Stough 2015; Stough and Kang 2015; Stough et al. 2016; Wolbring and Leopatra 2012).

2 Background

Latin America and the Caribbean Region (LACR) have the second largest amount of disasters per year (Correa 2011). In general, disasters include landslides, fires, drought, floods, storms, volcanic eruptions, earthquakes, and tsunamis. Data show a consistent upward trend in the number of disasters in the LACR from 1970 to 2009; the 1970s had an average

of 16 disasters per year and by 2009 that number had quadrupled to 63 disasters per year (Correa 2011). While this dramatic increase has been felt more moderately in Mexico, it is expected to increase as climate change worsens (The Global Partnership for Disability and Development 2009; The International Disaster Database 2009).

Mexico's top three climate related disasters are storms (43.5%), floods (24.4%), and earthquakes (9.5%) (The International Disaster Database 2009). As of 2014, mortality rates in Mexico attributed to disaster rank in the following order: flood (38.6%), storm (28.7%), extreme temperature (24.1%), landslide (3.7%), and earthquake (3.3%) (The International Disaster Database 2009). Although these data do not differentiate which populations are the most impacted, research shows marginalized populations such as PWD are at higher risk in disaster and emergency situations (Wolbring 2009; Wolbring and Leopatra 2012).

With a population of over 125 million, Mexico is considered “high risk” and ranked 43 out of 191 countries on the INFORM index scale. The INFORM index collates disaster variables including vulnerability, lack of coping capacity, hazard and exposure (Inter-Agency Standing Committee Reference Group on Risk, Early Warning and Preparedness and the European Commission 2019). Hazard and exposure are Mexico's weakest variables as this metric is nearly double in comparison to its seven most proximate “global peers” on the INFORM index¹ (Inter-Agency Standing Committee Reference Group on Risk, Early Warning and Preparedness and the European Commission 2019). While ranked “high risk,” Mexico also has some of the most sophisticated risk management tools and forward-thinking policies related to disaster financing (World Bank 2016). This context presents an interesting opportunity to improve efforts toward disaster risk reduction and disaster preparedness for marginalized populations such as PWD (Saldana-Zorrilla 2015; World Bank 2016).

2.1 Definitions and prevalence of disability in Mexico

The overall prevalence of disability in Mexico is estimated to be 5.1%, while the indigenous Mexican population endures a higher prevalence of 7.1% (Hugo et al. 2017; Instituto Nacional de Estadística y Geografía 2010). The two largest age groups of people with disabilities in Mexico are 30–59 years old (32.8%) and 60–84 years old (40.7%) (Instituto Nacional de Estadística y Geografía 2010).

The United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) defines persons with disabilities as “those who have long-term, physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis as others” (United Nations 2006; Lunga et al. 2019). For the 2010 Census, Mexico categorized and defined PWD into eight categories: limitation in activity, limitation in walking or moving, limitation in sight, limitation in speaking or communicating, limitation in hearing, limitations in tending to personal care, limitations in paying attention or learning and mental limitations.

Out of Mexico's 125 million people, the 2010 Census reported 2,416,807 individuals report having a mobility disability, 1,288,880 a visual limitation, and 221,690 limited personal care (Instituto Nacional de Estadística y Geografía 2010). From these three categories, a total of 3,927,377 PWD in Mexico are potentially vulnerable due to lack of effective

¹ Mexico's most proximate global peers according to the INFORM Index are: Zimbabwe, Guinea-Bissau, Malawi, Palestine, Azerbaijan, Cambodia.

preparedness activities prior to a disaster. The neglect of PWD is not isolated to inadequate emergency relief resources. According to Paz-Castro et al., people with disabilities globally “experience higher levels of poverty” and have mortality rates “two to four times higher than people without disabilities” (Castro et al. 2017; Stough and Kang 2015). More specifically, Hugo et al. state “a total of 23.1% of the Mexican population with disabilities, > 15 years of age lack access to formal education and their participation in economic activities is 39.1% compared with 64.7% of their counterparts without disabilities” (Hugo et al. 2017). These factors among many others—such as economic vulnerability, environmental vulnerability, biological and geological hazards—all contribute negatively to the overall disaster risk related to PWD (The Sendai Framework for Disaster Risk Reduction 2015).

2.2 Climate adaptation efforts and legislation

The Mexican National Civil Protection Agency (SINAPROC) was created as a task force in the wake of the 1985 earthquakes to manage disaster risk reduction in Mexico (The American Red Cross and the International Federation of Red Cross and Red Crescent Societies 2019; Gobierno de México 2019a). In 2007, Mexico ratified and signed the United Nations Convention of the Rights for People with Disabilities (UNCRPD). This convention was established to address and fulfill human rights of people with disabilities related to access to education, employment, healthcare and emergency services. Article 11 of the Convention mandates signatories to “guarantee the security, protection of people with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies and natural disasters” (United Nations 2006).

After Mexico signed and ratified the UNCRPD, additional policies and task forces were established to comply with the new UNCRPD protocols. In 2009, the National Council for the Development of People with Disabilities (CONADIS) was established. The purpose of the Council is to “establish public policy for people with disabilities, as well as promote their human rights, their full inclusion and participation in all areas of life” (Gobierno de Mexico 2009b). Following the establishment of this council, the following policies and advocacy groups were also established: the *General law for the inclusion of people with disabilities*, the Mexican Coalition for the rights of people with disabilities (COAMEX), *Norma Mex NMX-R-025-SCFI-2015* in the protection of labor equality and *Norma Oficial Mexicana NOM 008-SEGOB-2015* in the protection of PWD in “the civil protection field” in an emergency or disaster situation (Coalición México por los derechos de las personas con discapacidad 2017; *Ley general para la inclusión de las persons con discapacidad* 2015; *NORMA Oficial Mexicana NOM 008-SEGOB-2015* 2015). One other relevant council that is involved in the promotion of the rights of people with disabilities in Mexico is the National Council for the prevention of discrimination (Consejo Nacional para prevenir la discriminación 2017).

The legal document most relevant to this discussion is the *NORMA Oficial Mexicana NOM 008-SEGOB-2015*. In this document, Civil protection (SINAPROC) is mandated with the responsibility of protection and facilitation of emergency and disaster preparedness in Mexico. Additionally, the document requires each establishment or institution to create a “civil protection committee” that is in charge of evacuation and protection of PWD in case of disaster or emergency situations (*NORMA Oficial Mexicana NOM 008-SEGOB-2015* 2015). Many state entities have published online resources to support the community in disaster and emergencies. For example, Mexico City published the *Guía*

general de prevención y preparación en situaciones de emergencia para las personas con discapacidad [General guide of prevention and preparedness in emergency situations for people with disabilities]. This guide was designed to prevent, prepare, and raise awareness around people with disabilities in emergency & disaster circumstances (Secretaría de Gestión Integral de Riesgos y Protección Civil 2015).

Additionally, SINAPROC's collaborative report with the American Red Cross (ARC) in Mexico, entitled "Recomendaciones básicas para interactuar con personas con discapacidad en caso de sismo," lays out nineteen recommendations for people with disabilities in the case of an earthquake. The nineteen recommendations also fit succinctly in Zedillo et al.'s work regarding disaster preparedness behavior recommendations. Zedillo et al. divided these recommendations into three categories: plan of evacuation, early alert systems and security of infrastructure (Sanchez Hernandez 2018; Zedillo Ortega and Gomez Bruera 2018).

Similar to Zedillo et al., the American Red Cross outlines these prevention planning behaviors with emphasis on the importance of plan customization to each individual and encourages empowerment of PWD to do some of this prevention work independently and/or with assistance from a rehabilitation or disaster agency worker. And finally, a more recent global initiative that highlights PWD in disaster and emergency contexts is the Sendai Framework for Disaster Risk Reduction (SFDRR) 2015–2030. The SFDRR was established by the United Nations Office for Disaster Risk Reduction and is significant in "establishing PWD as legitimate stakeholders" in disaster risk reduction (The Sendai Framework for Disaster Risk Reduction 2015; Stough and Kang 2015). While these inclusive advances in disaster risk reduction are significant, insight drawn specifically from PWD still remain as a pivotal part of the process that is not being met. This research brings the experiences and insights of PWD to the forefront.

3 Framework

The study was informed by two theoretical frameworks: Bronfenbrenner's bioecological systems theory and the social model of disability (Boon et al. 2012; Creswell 2014; Oliver 1990, 2013). This study observes the relationships between the systems outlined in Bronfenbrenner's bioecological framework, which has been consistently used in emergency and disaster resilience literature. According to Boon et al., individual resilience is best defined as "the capacity for successful adaptation, positive functioning or competence despite high-risk status, chronic stress or following prolonged or severe trauma" (Bonanno 2004; Boon et al. 2012, p. 383). This individual resilience as noted by Boon et al., is a result of the interaction across multiple levels of Bronfenbrenner's bioecological model through individuals engaging in positive behavioral choices related to resilience (Boon et al. 2012). Individual resilience in emergency and disaster scenarios is contextually influenced by community level influences within the mesosystem and microsystem, institutional level influences such as hospitals and social services within the exosystem, and lastly through general societal views and policy influences within the macrosystem (Boon et al. 2012). Apart from the microsystem or the individual level, the mesosystem includes community level stakeholders such as family, school and neighborhoods. The exosystem includes hospitals, government agencies and other social services, and the macrosystem includes the broader societal, economic and cultural context.

The social model of disability is expressed by scholars as a view of disability which is understood “in terms of social conditions that marginalize minorities” rather than “biological conditions that disadvantage individuals” (Silvers 2003; Amundson and Tresky 2007). This study was designed on the premise of “shifting focus” as described by Priestley and Hemmingway in 2006, “the shift of emphasis, from individual to the social, has allowed activists, academics, practitioners and policy makers to engage in a far-reaching critique of the ways in which people with perceived impairments are affected by different social arrangements, and to envisage more inclusive alternatives” (p. 4).

The focus population for this study was originally people with mobility disabilities (PWMD), operationalized as inclusive to any individual with a mobility disability, who may or may not use assistive technology such as wheelchairs, walkers or canes. Following participant feedback, the study protocol was amended to include people with “visual limitations.” Participant feedback emphasized that individuals with visual limitations encounter similar mobility barriers as to those with limitations in walking and moving. Participants also suggested this inclusion to incorporate more diverse perspectives and manifestations of disability. Accordingly, terminology was updated to people living with disabilities (PWD) rather than PWMD. Additionally, PWD was utilized rather than people with mobility impairments (PWMI) in accordance with the social model of disability, understanding disability not as the antithesis of health, but rather the lack of accommodation made toward diversity for people of difference (Amundson and Tresky 2007; Campbell and Stramondo 2017; Kahane and Savulescu 2016; Oliver 1990; Silvers 2003).

3.1 Positionality of principal investigator

Positionality of qualitative research is critical in all aspects of the methodology and analysis. The principal investigator (PI) identifies as a white, middle class, cisgender female from the United States. She is not disabled, therefore, does not and will not ever fully understand the lived reality or phenomenology of person with a disability, despite the efforts to do so ethically and self-reflectively throughout this study. Due to this lack of similarity with the intersectional identity of each of the participants, the PI relied on the input of various rehabilitation professionals, persons with disability and cultural brokers for the design and methodology of this study.

4 Methods

The study locations selected by convenience sampling were the coastal town of Zipolite, Oaxaca, Mexico and the largest northern urban city of Tijuana in Baja California, Mexico. This qualitative exploratory study had two aims: firstly, to identify barriers for rehabilitation professionals in facilitating emergency and disaster preparedness for PWD in Mexico and secondly, to identify and describe the needs of PWD through community input. Aim one was addressed through a survey disseminated to rehabilitation professionals and aim two was addressed through a semi-structured interview format with PWD to discuss their perspective on emergency and disaster preparedness. The survey used to address aim one was originally planned to be a stand-alone research tool; however, due to challenges related to survey dissemination, the survey was utilized as a triangulation tool for the data gathered for aim two. This study was approved by the San Diego State University Institutional Review Board (HS-2019–0114).

The inclusion criteria for aim one's survey were rehabilitation professionals who were previously surveyed in the *Emergency relief for individuals with mobility needs survey* conducted in September 2016 by the International Society of Wheelchair Professionals (ISWP). From this previous globally disseminated survey, only eight professionals from Mexico responded. Thus, our starting reach sample size was $N=8$. Additional respondents were acquired through convenience sampling of rehabilitation professionals through social media and queries to other rehabilitation agencies. Between the two sources of recruitment, the previous survey and convenience sampling, the inclusion criteria were defined as any of the following: an individual who self-categorized as wheelchair service professional, rehabilitation specialist, non-governmental worker and/or public health professional. The participant was required to be 18 years or older and currently working in Mexico.

Utilization of a sample size calculator was not appropriate for this survey due to the following three limitations: (1) This study is exploratory in nature, (2) no published data exist on the population of rehabilitation specialists or wheelchair professionals in Mexico, and (3) the literature does not provide sufficient support for a metric that would validate the appropriate sample size for surveys-inclusive to both open ended and closed ended data (Viechtbauer et al. 2015). Due to the limited respondents in the recruitment process, the research team decided the survey would only be used as a source of triangulation for aim two.

The survey was disseminated via Qualtrics through email. Survey participation did not include any incentives and was completely voluntary. This methodology was chosen strategically to minimize the participant burden and to allow for an in-depth research focus for the semi-structured interviews in aim two. The survey was conducted in Spanish and was open from June 2019 to September 2019. Face validity of the survey was established through dialogic engagement with study committee and other rehabilitation professionals. Through stakeholder feedback, the survey went through several iterations to maintain the fidelity of the survey. Survey questions are provided in Table 1.

The goal of aim two was to identify and describe perspectives of PWD in relation to emergency and disaster preparedness. The study population for the semi-structured interviews in aim two was PWD who live in Mexico, 18 years old or older, who have either endured a disaster with their disability, acquired their disability through a disaster or have not yet experienced a disaster. The specific inclusion criteria were people with mobility disabilities and visual limitations and/or individuals who use assistive technology such as canes, crutches, splints, prosthetics, walkers, walking sticks, as well as those who are unable to procure such devices due to lack of resources, but who still have limitations in mobility and/or visual capabilities. The justification of focusing on these two manifestations of disability for this study was provided through iterative participatory feedback from the study population. Participants noted this feedback as a means of being more inclusive to diverse experiences of disability and due to the similarities in the challenges related to mobility disabilities and visual disabilities.

Participants were recruited through convenience sampling and were informed that their responses would be confidential. The PI spent five weeks volunteering in the local community in Oaxaca and two weekends in Baja California, at which time participants were asked if they would like to participate in the study. Snowball sampling was also utilized. As aim two utilizes a qualitative framework, the focus sample size was 8–12 semi-structured interviews. The desired sample size was reached ($N=11$). This sample is appropriate according to Creswell and Morse's guidelines for qualitative study designs (Creswell 1998; Morse 2000).

Table 1 Survey

<p>Basic information</p> <p>1A. What do you do for work? Select all the options that apply; you can select more than one option.</p> <p><input type="checkbox"/> Non-profit worker</p> <p><input type="checkbox"/> Wheelchair service professional</p> <p><input type="checkbox"/> Public Health professional</p> <p><input type="checkbox"/> Rehabilitation Specialist</p> <p><input type="checkbox"/> Other</p> <p><input type="checkbox"/> None</p> <p>2A. What state in Mexico do you work in?</p> <div style="border: 1px solid black; height: 20px; width: 100%;"></div> <p><input type="checkbox"/> Not Applicable</p> <p>3A. How much training have you had in disaster preparedness and emergency relief for individuals with mobility impairments¹/disabilities?</p> <p><input type="checkbox"/> No training</p> <p><input type="checkbox"/> Little training</p> <p><input type="checkbox"/> Moderate training</p> <p><input type="checkbox"/> Sufficient training</p> <p><input type="checkbox"/> Proficient training</p> <p><input type="checkbox"/> Unsure</p> <p>Provision of emergency and disaster preparedness resources</p> <p>4A. Do you believe it is the responsibility of wheelchair service professionals to provide emergency and disaster resources for people with mobility impairments¹/disabilities?</p> <p><input type="checkbox"/> Yes</p> <p><input type="checkbox"/> No</p> <p><input type="checkbox"/> Unsure</p> <p>4B. If yes, please check the items you think wheelchair service professionals should provide:</p> <p><input type="checkbox"/> Information about how to conduct a personal assessment</p> <p><input type="checkbox"/> Information about the use of personal networks</p> <p><input type="checkbox"/> Information about community disaster plans</p> <p><input type="checkbox"/> Information about disaster and emergency assistance programs</p> <p><input type="checkbox"/> Information about emergency plans, supplies, evacuation routes</p> <p><input type="checkbox"/> None</p> <p><input type="checkbox"/> Other- Please describe:</p> <div style="border: 1px solid black; height: 20px; width: 100%;"></div>

Table 1 (continued)

Regional disaster and emergency issues

5A. What are some common emergency preparedness and disaster threats for people with mobility impairments¹/disabilities in the area where you live and work?

Not Applicable

6A. Do you provide any information regarding disaster preparedness or emergency relief to clients with mobility impairments¹/disabilities?

Yes

No

6B. Mark all the types of information that you provide to your clients with mobility impairments¹:

Information about how to conduct a personal assessment

Information about the use of personal networks

Information about community disaster plans

Information about disaster and emergency assistance programs

Information about emergency plans, supplies, evacuation routes

None

Other:

6C. Please explain the reasons you do not provide information about disasters and emergency preparedness to people with mobility impairments¹.

Challenges and barriers to emergency planning for people with mobility impairments¹

7A. From your perspective, are there challenges for people with mobility impairments¹/disabilities to create an emergency plan on their own or independently?

Table 1. Continued

Yes

No

Unsure

7B. If you believe there are challenges for people with mobility impairments¹ to create an emergency plan, what are those challenges? Please explain below.

Table 1 (continued)

8A. From your perspective, are there challenges for people with mobility impairments¹/disabilities to access information about disaster and emergency assistance programs? Please explain.

Yes

No

Unsure

8B. If you believe there are challenges for people with mobility impairments¹ to access information about support programs for emergencies and disasters, what are those challenges? Please explain below.

9A. Personal Assessment: “A personal assessment is a tool used to identify needs and resources required for people with mobility impairments in a disaster environment. It can be created into a list of needs that describe your current capabilities and the assistance you will need. This assessment should be based on your lowest level of functioning” (Special Needs Emergency Preparedness, 2019).

From your perspective, what is required for people with mobility impairments¹/disabilities to create a personal assessment for emergency and disaster situations?

Not Applicable

Unsure

Final Comments and Perspectives

10A. Our goal in this survey was to explore perceived barriers, recommendations and perspectives of rehabilitation professionals and wheelchair service providers regarding emergency disaster preparedness and emergency plan creation for people with mobility impairments¹/disabilities. Is there anything else you would like to add in regards to emergency and disaster planning for people with mobility impairments¹?

10B. If you are willing to be contacted for a follow-up interview, please provide your email address below.

¹ the word “impairments” was used in the survey, as this survey was designed before acquiring input on this language from PWD during data collection.

Data collection was completed through a 30–45-min semi-structured interview. Semi-structured interviews were determined to be the most effective way to capture the perspective, lived realities and recommendations of PWD in the context of disaster and emergency preparedness. All interviews were conducted in person between May 2019 and July 2019. The subjects received \$10 USD or \$200 pesos as participant payments. They were completed in Spanish, in a private space where the participants lived, worked and/or volunteered. Transcripts remained in their original linguistic form (Spanish) throughout analysis and were not translated. Due to the PI's non-native bilingualism and translation of data from Spanish into English for the sake of analysis and publication in English, linguistic understanding in English may not be as nuanced as intended in its original Spanish. The interpretation and translation relied on the non-native professional level bilingualism, both in oral and written capacities of the PI.

The interview questions were loosely based off a qualitative study conducted in the USA by Rooney et al. in 2007 which focused on “difficulties faced by persons with mobility impairments” in relation to disaster preparedness (p. 206). Rooney et al. developed their interview questions through an advisory team of individuals which, according to the Bronfenbrenner's bioecological framework, included stakeholders from all four main system levels: microsystem, mesosystem, exosystem and macrosystem levels (Rooney and White 2007). The interview guide for this study was reviewed by the research committee which included a wheelchair user, several public health and rehabilitation professionals. From this iterative process of dialogic engagement with stakeholders, questions were modified to more effectively probe the aim of the interviews. In the interviews, all questions were asked of each of the participants, variance occurred with regard to the type of probing follow up question, as the discussion evolved by response to the main questions. The interview guide is shown in Table 2.

This study utilized a phenomenological approach in the analysis to understand and uncover the “lived reality” of PWD in a disaster context as it relates to disaster preparedness (Thorne 2000). A basic open descriptive coding method was used, and four initial coding rounds were completed by the PI before consulting a colleague and a cultural broker in peer briefings. The first few coding sessions involved a data reading and tallying of the frequency of each code. Every coding session was accompanied by research memos which noted patterns and repetitive language used by the participants. The first coding session yielded 23 individual codes. The second coding session was simplified to 15 codes, which included: accessibility, isolation, support, specific storm events, community, consciousness, emergency, empathy, environmental phenomenon, lack of resources, connectedness to others, common sentiments, evacuation, advantages and disadvantages for PWD and visibility. By the third and fourth coding sessions, the process switched to NVivo as code refinement became more specific. Individual codes were gradually grouped into five potential themes. The third coding session yielded fourteen codes from the previous distillation. The fourth round of coding solidified the formation of five themes encompassing the previous codes from coding session three. Upon completion of the fourth round of open descriptive coding, dialogic engagement and peer briefing began with the research committee. Transcripts were sent to a peer researcher to review for emerging codes with the plan to discuss after review. Initial codes and themes discovered by the PI were not shared with the peer briefer to avoid biasing the confirmability of the researcher's initial findings. The fifth and final round of coding informed by peer researcher iterative feedback provided the final five themes and codes therein.

In summary, utilizing a phenomenological approach, there were three rounds of data readings, five iterative rounds of descriptive coding, dialogic engagement, structured reflexivity

Table 2 Interview guide

Semi-structured interview questions

(1) How would you define disaster or emergency?

Specific Probe: What would some examples be?

General Probe: Tell me more.

(2) Have you experienced a disaster?

General Probe: Have you experienced an emergency situation?

Specific Probe: Did you have your disability or assistive device at the time?

Specific Probe: When and where was it?

Specific Probe: If you feel comfortable, please share your experience.

(3) Have you been provided information on how to prepare and plan for emergency and disaster situations?

Comprehension Probe: For you, what does it mean to be prepared for a disaster or emergency?

Specific Probe: Was the information you received, relevant to you?

Specific Probe: If received information on how to prepare, who helped provide information?

Specific Probe: Was it specific to you or people with disabilities?

(4) Have you received assistance to create an emergency and disaster preparedness plan?

General Probe: Please tell me more.

Specific Probe: How about conducting a personal assessment—have you thought about what you might urgently need in a disaster?

Comprehension Probe: What does a personal assessment mean to you?

Specific Probe: Do you know of who you would contact or how to get a hold of someone in the case of an emergency?

(5) What resources would be helpful for you to feel more prepared in an emergency or disaster? Do you have any suggestions of what support is needed from rehabilitation professionals or other support agencies?

a. Paraphrasing Probe: Can you repeat the question I just asked in your own words?

b. General Probe: What new directions should be explored to help PWD survive disasters?

c. General Probe: What lessons did you learn about disasters or situations of emergency that are important for others to know?

d. General Probe: Are there resources you feel should be offered for PWD in disasters and emergency preparedness?

e. General Probe: Are there current barriers or inaccessibility issues that stand out the most to you?

(6) Our goal in this survey was to “describe perspectives of PWD in regard to emergency & disaster preparedness and if other resource support is needed”—To this purpose, do you have any other suggestions or thoughts to add?

(Rooney and White 2007)

processes by the PI, and peer briefings with the research team and cultural brokers. Furthermore, triangulation from the surveys in aim one and field notes were used to confirm the trustworthiness, confirmability and dependability of the analysis. Through in-depth dialogic engagement, several iterations and theme adjustments were made resulting in five confirmed themes. Member checks and participant validation with transcripts were not utilized as a strategy toward confirmability due to time limitations of this study.

Table 3 Gender and mobility device specifications of participants

Gender	N	Mobility device	N
Males	7	Electric/motorized chair	1
Females	4	Manual chair	4
Total	11	Other mobility devices	4
		Cane	2
		Total	11

Table 4 Geographic location of participants

Geographic details	N
Oaxaca, Mexico	8
Baja California, Mexico	3
Total	11

5 Results

In aim one, thirteen participants started the survey, of those, five were incomplete, and two were duplicates, for a total of $N=6$ surveys for analysis. Only two of the respondents participated in ISWP's prior survey, *Emergency relief for individuals with mobility needs survey* conducted in September 2016. Use of this survey is extremely limited; however, it was utilized for triangulation of the interviews in aim two.

For the main focus of this study, the interviews in aim two, the sample size was $N=11$. The gender, mobility device specifications and geographic information of the participants are listed in Tables 3, 4.

5.1 Theme one: holistic inclusion for PWD in disaster and emergency scenarios

The most prominent emerging theme was a robust understanding of inclusion, entitled "holistic inclusion." This theme was provided by the participants as a conceptually rich four layered understanding of inclusion supported by the following concepts: visibility, awareness and consciousness, sensitization and empathy, and support. These concepts were described by participants in the context of disaster and emergency preparedness but also within their general daily life.

The holistic inclusion theme first emerged in research team briefings through recognition of several concepts being referenced consistently by participants. The aforementioned concepts, (1) visibility, (2) awareness and consciousness, (3) sensitization an empathy and (4) support, were often used interchangeably by participants. Although initially it seemed participants were using these terms synonymously, it emerged in analysis that they were using all these terms to reference inclusion as a whole, and not synonymously. The participants were defining inclusion in a variety of ways. Thus, these multiple concepts formulated a layered understanding of inclusion. The holistic inclusion model in Fig. 1 depicts the theme of holistic inclusion as described in the following paragraphs (Table 5).

5.1.1 Layer one: visibility

Interviewees discussed visibility as isolation or being alone and the need to be visible or be seen. Being visible as a community member with diverse needs was described by participants as an unavoidable step to truly consider a situation or plan as “inclusive.” For a situation to be inclusive, the PWD must first be known by their community. This was also mentioned in the aim one survey and was used as triangulation to confirm the importance of this code in analysis. The survey respondents from aim one mentioned “making PWD visible as active individuals socially and economically”. This was used to validate the credibility of the data received through the interviews.

5.1.2 Layer two: awareness and consciousness

Awareness and consciousness was defined as having or lacking knowledge, awareness or consciousness of PWD in disaster and emergency contexts. After visibility is established, inclusion must continue to manifest itself through a heightened level of awareness. Participants defined awareness as an active process of mentally recognizing or becoming cognizant of the presence of PWD as part of the community, who also have requirements for resilience and survival. This code establishes confirmability in triangulation with the aim one surveys. The survey respondents mentioned several similar terms that were used in reference to PWD, such as “lack of knowledge/information” or “acknowledgement or ignorance of the subject.”

5.1.3 Layer three: empathy and sensitization

After visibility and awareness, the third layer is entitled “empathy and sensitization.” All participants commented on issues related to “empathy and sensitization” and did so in all of the interviews. Participants made a clear distinction from awareness and consciousness. While the code “awareness and consciousness” (layer two) is strictly the hard-cognitive recognition of PWD, “empathy and sensitization” requires emotional acknowledgement and subsequent response to PWD in disaster and emergency situations. The definition of this code was defined as sensitization and empathy or lack thereof, the phenomena of individuals wanting to help, and acting communally with a sense of connectedness built on awareness and care.

5.1.4 Layer four: support

Support was divided into five major subcodes due to the amount of references and saturation within this theme. These five categories are dependence, organizational support, governmental support, environmental support and accessibility and training and educational resources. The manifestation of support is an extension of the empathy layer; however, it is empathy in practice. The support layer is especially crucial as it transforms the process of inclusion into a tangible action that will directly impact PWD. This fourth level was confirmed through triangulation with the aim one survey targeting rehabilitation professionals. The rehabilitation professionals who participated in the aim one survey, all mentioned a need for resources, education, access to knowledge and accessibility.

The support layer builds upon the foundational structure of visibility, awareness and empathy. Catalyzing from visibility of PWD (core layer), holistic inclusion further develops into a healthy awareness and empathy of PWD (layer two and three), at which point support manifests for PWD (layer four). Layers one through three (visibility, awareness and empathy) demonstrate a more individualized and internalized process within the microsystem of an individual's perception toward people with disabilities. However, layer four, support, translates this internalized contemplation about PWD into a tangible external act of inclusion toward the community of PWD. From the support layer, we can see Bronfenbrenner's bioecological system in action, when the individual in the microsystem interacts with mesosystem and exosystem through interactions with community members, organizations, hospitals, government agencies (Boon et al. 2012). Participants did not explicitly build this model; however, it was evident in the coding process that participants were referring to these codes in semantic patterns. As such, the research team placed this described model in a visual format.

5.2 Theme two: evacuation

A second theme presented in the analysis was evacuation. The dilemma of staying or leaving was consistently mentioned as an issue in scenarios of hurricanes, tsunamis, fires, floods and earthquakes. Saturation on this issue was quickly noted, especially in the case of earthquakes. Over half of interviewees ($N=6$) expressed their frustration that evacuation announcements are only made to the "general public" and are not appropriate or applicable to them (PWD), as their functional ability is different from someone who does not have a disability. Respondents overwhelmingly noted that although evacuation is recommended for climate emergencies, it is often more dangerous to evacuate for PWD than it is to stay in place. Participants emphasized that the government, NGO's, and even other community members do not consider the diverse needs of PWD and consequently, they are often left behind or left to decide on their own. They describe this as a mental process of weighing their potential for survival in emergencies "due to their personal situation." A few selected quotes below reflect this sentiment.

"if the house shakes and falls, I stay here because, how do I get out? What is the advice for all of us people who have disabilities? It is difficult."

"As I have a disability, I can't run, then when I saw that the rain started, I enclosed myself inside. But later when I was very scared, I wanted to leave, and when I left to go outside my house, there were trees everywhere and I could not pass."

"I felt that the sea was going to come upon us, but where do I go? I said, well, I am not going to move, I am going to stay."

"The teacher was the only one who stayed there with me, and we didn't leave until it passed. But in emergencies, we always stay, we are always the last ones."

"When I take off my splint and tennis shoes, I no longer walk, I sit or lie down. And this was very difficult- I didn't have my tennis shoes on. So, all I did was get my family out- telling them to leave. But they told me: "but you also must leave!" and I said, me? but how? I can't get out? But I didn't tell them that because I did not want to stop them from leaving. I said it's no problem, I am not afraid— go outside...because I preferred them to be outside because they could walk — I couldn't. By the time I get my splint and tennis shoes on, it will be at the end of the tremor [laughs]."

Table 5 Theme one: holistic inclusion quotes

Visibility	<p>“In Oaxaca, in Mexico, we really do not know how many we are, for example. Then it is necessary as well, that the state responds to—and really how many people with disabilities live in what areas, in areas of disasters—there is none.”</p> <p>“There is a lack of visibility for people with disabilities when faced with an emergency, right? As in the previous case, that is, we are not visible, we are not a priority. There was a recommendation generated by some people, one was the question: how to get there or how to make visible people with disabilities who are in the ranches? It is necessary to do a mapping and for the authorities to do that. Map the elderly as well, and where they live in the ranches or if there are people with disabilities in the ranches and how, then, to get them...and if they require some more attention”</p> <p>“There is absolutely nothing, the authorities do not even see us, there are no censuses or data of those who, in the case of a contingency, who need help. They do not know who is there.”</p> <p>“But for example, we were making a lot of visibility for people with disabilities in the isthmus of Tehuantepec. Because if you don’t mention them, they’re not present, right? So, it was a recommendation or we were asked that a lot—to connect with people from there and who needed support and that it really reaches those who need it the most.”</p> <p>“And keep in mind that—people with disabilities have to be present that some can’t move, can’t run, can’t see, don’t listen well or can’t—they are deaf, right?”</p>
Awareness and consciousness	<p>“Well, first of all, to train conscientiously on the issue that there is a group that requires more help in the event of a disaster”</p> <p>“There are some people who are aware, others are angry—“you will destroy the sidewalks, right?” So, the ignorance of the people, as I say, or like—they say “I do not know much about the subject, right?”</p> <p>“But this, I feel is what I mean, because they don’t know: how-how to help the person with a disability, right? I mean, they have no idea”</p> <p>“I don’t know if they don’t realize it or don’t know—or they don’t know the issue, don’t they?”</p> <p>“My recommendation is to know the issue of disability, have more awareness”</p> <p>“Well, first train conscientiously on the subject that there is a group that requires more help before a disaster. In case of an emergency we are the ones left—the last. So, it is this creating equal alliances with the family of how to solve the issue, that is what is missing.”</p> <p>“Well, keep the issue in mind, right?—that there is a specific group that also requires the same attention, but adequate to their needs, no? Because for example a shelter for people with disabilities—if you are going to house someone with a disability it has to be accessible. Does it really exist? They don’t exist because it’s still an issue that’s not yet on the agenda. Right? No, it simply is not.”</p>
Empathy and sensitization	<p>“It is that there is not, there is not this, how do you say—there is no empathy, there is no empathy.”</p> <p>“One doesn’t live it, if they don’t feel it.”</p> <p>“Then all that then comes through empathy. That they don’t have the same, the same—what’s it called? The desire to help.”</p> <p>“Well, even if he had knowledge, or already knows how to help, even if he doesn’t have empathy—if he does things well then, you say ‘thank you’ -you know? But then if you are with someone that has the criteria to help another, it is worth more. Because many times people do not have a heart...I have seen many cases that are not good, I have not experienced it myself, but I have seen that an old lady who treats him badly, that he can no longer move. So, if a person is going to help you on X things and—and they upset you, what you can do? I would say—to have a little heart, empathy for others.”</p>

Table 5 (continued)

Support	<p>“That is what they do, if they see that there is no accessibility in that house, they give them the ideas of how to clean, how to fix it so that they have mobility.”</p> <p>“We need more sidewalks, we need more ramps to go up the sidewalks, because not all streets have them, if you walk on the curb and suddenly it is like that, and there is no ramp then you have to turn around”</p> <p>“So, there is also a lot to do, in the face of disability—the ways to do things because then there are more needs, no? For example, when they are severely disabled or elderly as well- they need diapers, medication-which is super necessary to have them before any contingency. That is what is missing- how to make a wheelchair, how to disassemble a chair because if you get in a car, or how others understand that you cannot move, and you have to take your chair, right? it is a priority of a physical disability. I think there is a lack of training on the subject.”</p> <p>“Also, any other emergency, you know? If it’s a disaster outside, you have a support network. They can support us in case of a disaster here, it can be rains or fires or whatever.”</p> <p>“Emergencies? Well, for emergencies we need some accessibility, accessibility so that you can leave. There are many programs in the United States that help you know how to move, transfer from bed to your chair, and all that. here in Mexico they don’t. I would say for Mexico, this one, that there needs to be something similar, because it is necessary. There are many disabled people who do not have the way or do not have the way to get an electric wheelchair or they do not know many times they are, as it is called, psychologically bad. I cried for four years. depressed in bed, but did not want to know anything and now it’s been two or three years I’ve been moving. There are many people who can’t say that. And well, we need this support, more to be do all these things.”</p>
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5.3 Theme three: emergency planning

A third emerging theme was emergency planning behaviors and recommendations. All of the interview participants had recommendations toward entities in the exosystem, mesosystem and microsystem of Bronfenbrenner’s bioecological system. The official definition of this theme was any suggested or recommended idea, preparedness behavior or solution for how to improve services or preparedness for PWD in emergency and disaster situations. This may include but not be limited to suggested mapping, census, phones, radio, shelters, alerts, emergency food, dispensary, cars, credit on phone, storm warnings, and governmental support before the disaster, etc. Some of the preparedness behaviors and resource recommendations provided by the participants are listed below, followed by several quotes. These suggestions were probed originally from the following interview guide questions: (1) “What resources would be helpful for you to feel more prepared in an emergency or disaster? (2) And do you have any other suggestions or thoughts to add?”

6 Emergency planning behaviors and recommendations

1. Ask what people actually need
2. Authorities need to visit and see the pueblos/communities
3. Have preventative information of what to do before a certain situation

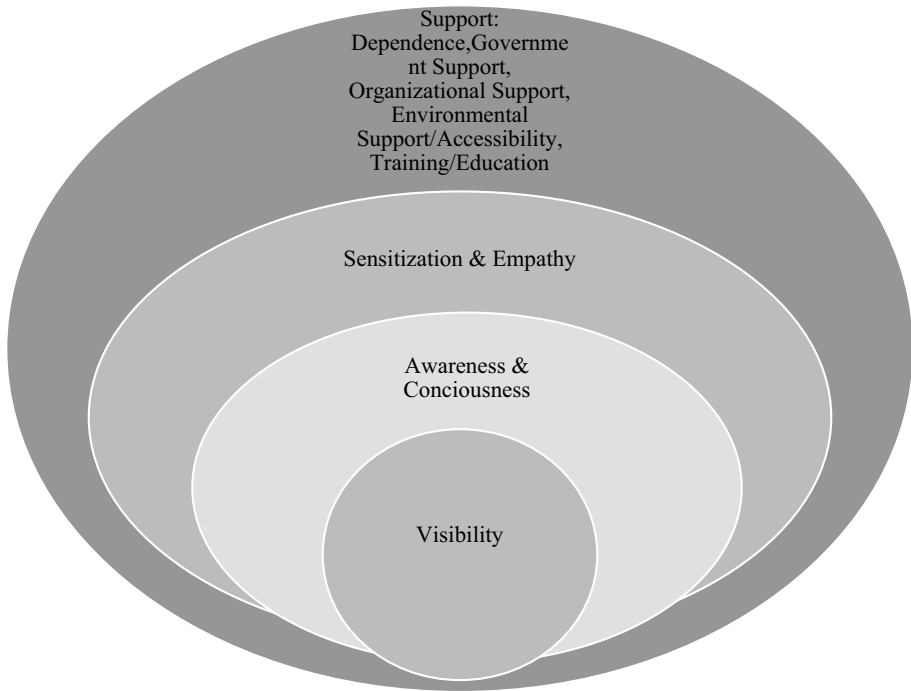


Fig. 1 Holistic inclusion model for disasters and emergencies for people with disabilities

4. Authorities need to understand the theme of disability (inclusion, sensitization and awareness)
5. Inclusive trainings for the community and PWD
6. Follow up after trainings
7. Organize the community and create alliances and involve all groups (PWD, other community members and organizations, schools, government agencies, churches, etc.)
8. Detection of the zones and better communication
9. Supplies: phone with credit, radio, food
10. Support, accessibility/environmental structures and adaptations for PWD (i.e., ramps, handrails, pavement, other protections, evacuation vehicles for the community, shelters that are accessible)
11. Shelters and evacuation locations
12. Mapped out locations of residences of PWD
13. Current trainings are not efficient, better information is needed

“And as appropriate, its context is super important right? The area, in case of emergency—context or how to consider the people of the community. And how can you make alliances to carry out a job?”

“The information they give is very poor. I think. No—they don’t follow up with you, no—I’m going to say that they should follow up so that people can understand the whole process because many don’t do it”

“Involve doctors, and here involve the priests, right? Because Both doctors, teachers and priests have a very strong role in the community. So, it would be good if they were also informing, you know. More than anything, the teachers in the schools.”

“Many of them, do not. They become blind. But if there is, there is a regulation—I think—that they have to have accessibility. No? If you are going to build something, you have to have accessibility. In this world almost half of us are with people with disabilities, that is, and apart from that, aren’t we all going to become old? One day we will be eighty years old and we will need a chair or something. but then I tell you the ignorance, of the people, sometimes do not see beyond if not today. What is present today but I don’t know what will happen tomorrow. So, if it is, it’s a little bit- I tell you I fought with people who didn’t want to put ramps. Yes, Pina was fighting, fighting until they succeeded. Yeah, it’s a bit difficult.”

“I want the community to be organized, right? The authorities come to organize with the community but within that plan, consider people with disabilities and help them, if they have to be carried, move them at home in a wheelchair or a car or a vehicle to move it to another place or a shelter. The police must participate, civil protection must participate.”

“Make shelters adapted for people with disabilities because they make shelters in the hills.”

6.1 Theme four: collective memory

The fourth theme is related to the collective memory of storms and events. In discussion with interview participants about disaster and emergency preparedness, the names of the storms were frequently referenced with a deep sense of connection and familiarity. Specific storms undeniably struck the heart of the community, eliciting not only cognitive engagement with the idea of preparedness behaviors but also a strong emotional response as to what it means to reduce disaster risks. Many interviewees discussed structural changes made within their homes and the local community due to past disasters that devastated their community. Participants discussed many ways in which their communities were rebuilt with the learnings of the past.

A significant storm for the coastal Oaxaca participants ($N=8$) was Hurricane Paulina (Hurricane Pauline as referred to in English). In 1998, Hurricane Paulina struck the Oaxaca coast in October 1997 and caused “catastrophic levels of damage and loss of life” (Meli 1998). The final death toll was recorded at 272 with thousands initially missing in the days after the hurricane (Longshore 2008). All participants ($N=8$) from this region mentioned Hurricane Paulina at least 3–4 times each in the interviews. The resounding repetition and reference to Hurricane Paulina in the interviews shows the significant role extreme weather events play, even decades later and how those resonate with the community. This traumatic experience emerged as a significant collective memory in the community and as an important point of reference. Data regarding this theme were also triangulated from field notes. An excerpt of some of the accounts related to Hurricane Paulina are below.

“If it rains, when it rains, it rains very hard and hurricanes always come. And well, I had never seen a hurricane—until when the famous Paulina came, which was like ’98. It was a very strong hurricane, so strong—where I thought I was going to die. Because nobody was prepared, nobody explained to us what it was like or what to do at the time. Since I have a disability, I can’t run so when I saw that the rain started, I locked myself in but then I got very scared I wanted to go out, and when I went out-

side my house, there were trees everywhere and I couldn't get through.”

“Well, this hurricane Paulina, in the year ninety-seven. I was with my family in my house, I tell you we did not know what will happen but the authorities warned us. Hurricane Paulina passed but we knew the intensity, how strong the wind was, but we did not know the impact. So, if we meet (with the storm), what will happen if we stay in the house, and I remember my house was made of metal sheet, the wind comes and [chhheeeeww] Fly the sheet. [cheeeww] Fly all of them.” I remember the laminate fell on my arm. At that moment we tried to leave, we went to another safe house made of stone and strong cement. We went to protect ourselves in a bathroom. And after we passed a tree fell right where we passed on the road, there was a tree. The desperation and anguish, anxiety was very strong, because the wind [noise of wind] also came with very strong rain and all the animals were taking refuge. But why didn't we take the recommendations into account? Many times because of ignorance, you don't know the impact of the wind, which moment it comes, and the intensity is very strong... And my mom and my brothers, sisters— I still didn't have a wife— but my brothers went out later during the hurricane with the wind... We went about fifty meters from there to my house, there is a small bathroom, a lower part of the house. but the bathroom was completely concrete throughout. There we protected ourselves for a while. And then we went to another house but because we had ignored the recommendations. Now if they say hurricane we know what will happen. If they say category two, three ohh very strong. And after that hurricane in 97'- others came Carlota, Rick, a month passed another. So, recommendations are very very different as well. Another month also passed with pure rain in '97, but we already knew what was going to happen. You save some food, you save water to drink. Preventing before is very important, that's why information, prevention is important because you can save your life.”

6.2 Theme five: uncharted disaster territory

The final and fifth emerging theme was named “uncharted disaster territory.” Triangulated from field notes, respondents consistently mentioned the novelty of powerful storms within the last two decades. This theme paralleled theme four (collective memory), but is separate as its focus is not on the storm itself, but rather the novelty and a need for adaptation and mitigation strategies within the community. The majority of participants who mentioned Hurricane Paulina referenced it as a turning point in their collective memory, marking it as the new status quo for the community which had not been experienced before. All participants in Oaxaca ($N=8$) described storms prior to Hurricane Paulina as “a time before” and how the storms of their ancestors were not as severe in comparison with their experience. The participants shared their lived experience as an abrupt new reality of a worsening climate, gradually occurring over the last several decades. Despite this significant shift, all participants noted never having spoken or discussed the topic of emergency and disaster preparedness in such detail or as it relates to their personal safety and preparedness.

“Some of us had commented that this had never happened, because everyone was surprised.”

“No— Well, of those who talked later—it hadn't happened, yes. Maybe more before. but of the old, for example, my Uncle or the elderly. It had never been seen.”

“No, it does not speak to us, we have not touched on this topic, but it is important.”

7 Discussion

In accordance with the results and themes provided by the participants, the research team collated the themes and uncovered four key findings from this study. The four findings include: (1) the extent to which disability is misunderstood, (2) the need for inclusive preparedness planning with the focus population, (3) the need for an intersectional approach toward preparedness planning initiatives and finally, (4) a need for urgent action in disaster risk reduction and promotion of preparedness behaviors.

7.1 First key finding: misunderstandings about disability

The first key finding concerns the extent to which disability is misunderstood in society. The lack of inclusion and fundamental understanding of disability highlights the need for following: (1) consideration to appropriate language use (2) recognition of the appropriate and inappropriate use of certain adjectives to describe disability.

“People first” language, as defined by the Centers for Disease Control and Prevention, is “the appropriate language use that emphasizes the person and not the disability” (Centers for Disease Control and Prevention 2019). Although people first language was not explicitly noted by the participants in the interviews, field notes by the PI documented this consistently as a topic of discussion among the community members. Various community members regularly asserted that it is imperative that society, especially those working with people with disabilities, listen to this discussion about “people first language,” coming from within the community. “People first language” is however, debated among scholars due to diversity in intersectional identity and demographic considerations. For example, to some individuals, people first language insinuates disability as a negative antithesis of health and lack of recognition of pride related to their identity. However, for this particular study, the participants clearly indicated that “people first” language was their preference, as modeled by prominent organizations such as the World Health Organization. Accordingly, this delicate situation and consideration to language use in each context requires awareness and empathy as noted in theme one. The right to self-determination with each person and their language preference must be acknowledged prior to engagement with the individual. These findings reassert the need for more participation of the community in general, as well as in disaster and emergency preparedness. Moreover, public service agencies involved in disaster preparedness for PWD must be informed by the theoretical understandings that exist in disability literature. Understanding of the social model of disability is required to reject the systemic discrimination of PWD and in order to influence more equity-based solutions, especially in moments of chaos (Peek and Stough 2010; Priestley and Hemingway 2006; Stough et al. 2016). Conclusively, more research needs to be done regarding semantics, what that means to each focus population and how it impacts public health outcomes related to disaster preparedness and resilience.

7.2 Second key finding: inclusive preparedness planning

The second key finding identified not only the needs of PWD but also, provided the rich discussion of inclusion in which their needs must be met. Theme one entitled “holistic inclusion” and theme three, entitled “emergency planning” drive this second finding. “Holistic Inclusion” emerged from the participants as a contextual framework that is integral to the delivery of resources and support. Participants resoundingly noted a layered

understanding of an inclusive context for PWD in disaster preparedness. Without such layers—visibility, awareness, empathy and sensitization and support—real approaches toward promoting disaster preparedness behaviors within the community would be incomplete and detrimental.

The need for robust disaster and emergency preparedness is not exclusive to PWD; however, as noted by Stough et al. (2016), it is “the nature of these barriers for participants with disabilities” that is different (Stough et al. 2016). Accordingly, two strategies can be utilized to address this distinction in the “nature” of the barriers (Stough et al. 2016). Firstly, as reflected in the holistic inclusion model from theme one, empowerment can be used as a means to establish visibility, participation and representation of PWD within the broader community. Representation and visibility can establish a better understanding of these barriers for PWD, and how to create participatory and inclusive strategies to dismantle them (Bevc et al 2014; Stough et al. 2016). The 2018 Disability and Development Report reaffirms aforementioned need to “Ensure that persons with disabilities participate in decision-making processes and are active stakeholders at all stages of disaster response and humanitarian action from planning to implementation, evaluation and monitoring” (United Nations 2018). This can be done through interventions targeted at self-efficacy and empowerment. A study showed in 2019 that among the population of PWD, interventions targeted at self-efficacy have potential for “significant impact on their level of preparedness” (Marceron and Rohrbeck 2019).

The second strategy would be implementation of integrated community education. This education would discuss diversity specifically as it relates to PWD and the social model of disability. As supported in the literature, a greater understanding of the social model of disability will create greater capacity for empathy, sensitization and support within society as a whole (Priestley and Hemingway 2006; Stough et al. 2016). For example, one of the study’s organizations who supported this study conducts these “sensitization workshops” for children who visit the facility in hopes to educate the community regarding the diversity that exists locally and around the world.

7.3 Third key finding: an intersectional approach

Theme two entitled “Evacuation” and theme three “Emergency planning,” collectively revealed the need for an intersectional approach toward disaster risk reduction for PWD. An intersectional and systems approach is needed to be more effective in disaster preparedness activities. The data and supporting literature affirm a lack of provision of disaster preparedness for PWD. This lack of disaster preparedness for PWD includes a lack of evacuation plans, transportation, “inadequate infrastructure,” coordination of infrastructure and services, etc. (Bevc et al. 2014; Fox et al. 2007; Stough et al. 2016). Similar to this study’s findings, absence of appropriate evacuation messaging and all the complexities therein leave PWD to weigh their options on their own, often inflicting lasting psychological harm on PWD (Peek and Stough 2010). In the words of Malpass (2018), “This complexity reinforces the need for meaningful engagement with individuals with a disability in emergency management planning to meet the range of functional needs and reduce risk for this population” (p.65). Every individual has different requirements; however, the literature indicates disaster risk reduction is overly simplistic and tailored to people without disabilities and thus requires an intersectional organizational, community and policy response (Lunga et al. 2019; Ronoh et al. 2015).

Lastly, Stough et al. (2010) also affirm this discussion point of a need for “awareness across agencies” (pp. 218–219). Stakeholders that need to be involved in this process should include but not limited to the following: PWD, disaster risk and reduction agencies, disability organizations, governments, public health & rehabilitation professionals. This call for a dynamic, intersectional approach rooted in a rich contextual understanding of holistic inclusion is validated in the existing literature and is noted previously as “community partnerships” and “consensus building on preparedness priorities” for promotion of preparedness behaviors (Bevc et al. 2014). If all stakeholders, inclusive to the focus population, collectively work toward minimizing risk with “speed, precision and coordination with other relief actors,” PWD may have a greater chance of survival and opportunity toward preparedness activities (Landry et al. 2016).

7.4 Fourth key finding: urgent action required

Finally, and most importantly, this study affirms a demand for urgent action and positioning toward the promotion of emergency and disaster preparedness as an integral form of disaster risk reduction in Mexico. This finding draws from theme four and five, in which the participants discussed their “collective memories” (theme four) and the novelty of the recent “uncharted disaster territories” (theme five). These two themes, showed similarity in reasserting the urgency toward climate action—especially for marginalized populations. The participant’s stories mirror the extreme changes occurring in our environment as a result of climate change (Allen et al. 2018; The Global Partnership for Disability and Development 2009). Furthermore, these data reiterate the required urgency in our communities especially with marginalized populations, as many are less likely to have access to “capital, resources and support” in order to be prepared for the “new normal” (Bethel et al. 2011, 2013). It requires we not only understand the “what” but also, the “why” and “how” in order to design and implement mitigation and adaptation strategies appropriate for diverse populations especially within vulnerable communities (Cohen and Brown 2012; Stough 2015). Reference Fig. 2 for a summary of the discussion points and findings.

8 Limitations

This study was exploratory in nature and limited in transferability to other locations. The semi-structured interviews were conducted in Mexico, eight from the coastal community of Oaxaca and three from the rural community in the border region in Baja California. These two locations reflect very different customs, culture, language, environmental threats, history, hazards and vulnerability, emergency preparedness policies, governance, civil protection coverage, community engagement and other important contextual variables. Participants in future studies should be equally stratified geographically to be more representative of the environmental threats, and other determinants of health in each region. Due to lack of time, there was no piloting of the original interview guide and there were no participant validation or member checks as part of the methodology. Although the interview guide and survey questions for aim one and two were validated by relevant stakeholders, all stakeholder archetypes may not have been included. Overall, if time allowed, this study would be strengthened by use of participant validation and member checks within the piloting stage and throughout the data collection process.

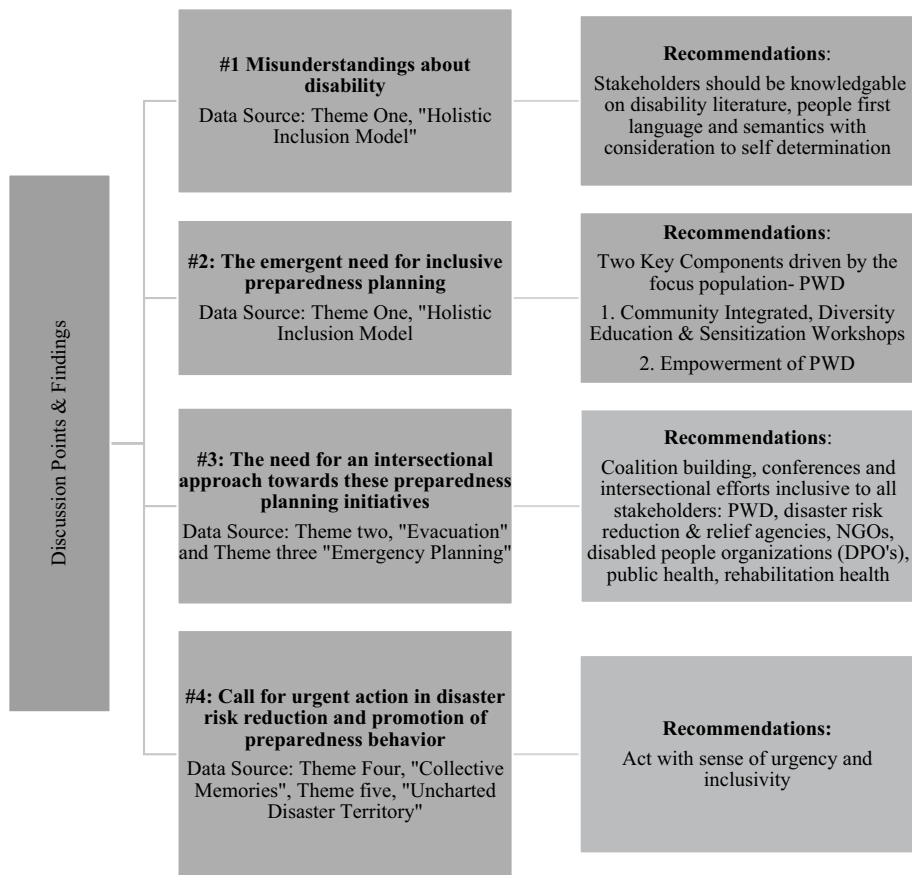


Fig. 2 Discussion points and findings *not listed in priority

Furthermore, this study would also be strengthened by extensive prolonged engagement with at least six months of observation (Lundy 2008). Linguistic interpretation also may have impacted the results as forward and backward translating by a native expert was not utilized. The interpretation and translation relied on the non-native but professional level bilingualism both in oral and written capacities of the PI. Additionally, the positionality of the PI is limited to the experience of a white, middle class, cis-gender female from the United States.

9 Conclusion and recommendations

It is critical that future research prioritizes the inclusion of the focus population in addition to all disaster risk reduction stakeholders relevant to the particular context (Stough 2015; Stough and Kang 2015; Stough et al. 2016). More research needs to be done in the field of health promotion related to influencing disaster and emergency preparedness behaviors in low-resourced settings.

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Author contributions NS and RP led study conceptualization with input from MG. NS collected, transcribed and coded data. NS and RP were involved in data analysis. NS drafted the paper, and RP and MG reviewed and suggested changes. All authors approved the final document.

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Data availability The datasets generated during the study are not publicly available to prevent disclosure of study participants.

Compliance with ethical standards

Conflicts of interest The authors have no conflicts of interest to declare that are relevant to the content of this article.

Consent to participate All participants provided written informed consent.

Consent for publication Participants were assured confidentiality and privacy even though information would be used for published articles or for presentations to other scientists.

Ethics approval This study was approved by the San Diego State University Institutional Review Board (HS-2019-0114).

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