

Research Articles and Essays

**Navigating Uncertainty: The Family Perspective of
Preparing for Crisis with a Disability**

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Abstract

Family disaster planning and preparation demands proactive acknowledgment and accommodation of individuals with disabilities. This study, based on interviews with families including members with disabilities, uncovers insights on information gaps, adaptive strategies, technology use, and support networks. Contributing to disaster and disability studies, resilience, and crisis planning, it highlights the effect of crises on family dynamics and the crucial role of early engagement of individuals with disabilities in disaster planning

Keywords: crisis preparation, disasters, disability-inclusive disaster risk reduction

Navigating Uncertainty: The Family Perspective of Preparing for Crisis with a Disability

The pandemic years and the war in Ukraine have left many of us with an increased awareness of the fragility of personal safety and national security. Even with the advancement of science and technology, there are things that can endanger most of us. For people with disabilities, this became acutely apparent when access to care, vaccinations, and in some cases, shelters were not equally accessible for all. For people living at home, in a family situation, a preparation plan could very well be missing (Barton-Hulsey et al., 2024).

Deinstitutionalization and community living mean that many people with disabilities live at home, with families or in single households. Some have personal assistance, and some have none. Some have family carers, and some have other arrangements (Orru et al., 2023). In the event of an emergency or disaster, a relatively independent person can become more at risk by the impact of unfamiliar hazards or difficulties. Activities that could be easily navigated in everyday life may suddenly present an obstacle impossible to mitigate.

Lindsay and Hsu (2023) describe how families with technology-dependent children confront distinct hurdles in disaster preparedness. They rely on different kinds of technology, such as medical devices or tools, to manage their health and daily lives. However, sustaining continuity of care and safety during crises can be very difficult for these families (Hamann et al., 2016). According to Lindsay and Hsu (2023), many families with technology-dependent children are unprepared for emergencies and have significant unmet preparedness needs. Certain people need hospitalization because of disaster-related power outages that impact the supporting technology they need to survive, emphasizing their

vulnerability during times of emergency. Other findings revealed that nearly half of the families queried had taken their child to the hospital because of previous power outages or planned to do so if power outages lasted for an extended period.

In times of crisis, relying on household members for assistance becomes even more important, particularly for people with disabilities. A study by Chang et al. (2023), highlights how a majority of respondents expect to seek support from their household members during emergencies. The disproportionate impact of disasters on people with disabilities reveals a social aspect of vulnerability where gaps in disaster risk reduction creates vulnerabilities for certain populations (Alexander et al., 2012 and Chadwick et al., 2022). To mitigate this, this study aims to find methods of capturing the lived experiences of people with disabilities in their home environment and identify areas of interest in collaboration with the families. With the pandemic as a backdrop and heightened awareness of preparedness issues, interviews with families with one or more disabled members can help improve knowledge about how different emergencies may impact the safety of such families. This study is part of a larger research project which investigates the use of structured ways to integrate people with disabilities into disaster risk reduction (DRR) activities. It uses interviews to investigate techniques for inclusive crisis preparation. The goal is to capture questions and problem areas, with individuals with disabilities and their families serving as active resources from the outset.

Methods

The current study used qualitative analysis to delve into the viewpoints on crisis planning and preparation within households where one or more members have a disability. It has an ethics approval and uses informed consent in all interviews.

Four semi-structured interviews were conducted with individuals with a disability in a family or those in a family-setting with experience of disability. This approach was chosen for its versatility in obtaining rich, nuanced observations. Participants were recruited from informal and professional networks within the disability community. Two male and two female respondents between the ages of 30 and 65 participated, all from different families. This study used in-depth interviews that lasted 45–60 minutes and were conducted online via Zoom. The participants were asked a variety of questions about disaster planning and how their families prepare and think about emergencies. An interview guide was used, and the sessions were recorded and transcribed using the software Whisperer. Braun and Clarke's (2013, 2021) six-phase process of reflexive thematic analysis was used: the transcribed material was analyzed by coding and interpreting patterns of meaning. Themes around these patterns were developed and used as a framework. The resulting themes were Awareness, Accessibility, Information, Technology and Strengths.

Results

Five broad themes were developed from the analysis. The findings include awareness of the need for crisis planning, information shortages, adaptive methods, technology utilization, and informal support networks for people with disabilities and their families in crisis preparation.

Awareness

The participants demonstrated an awareness of the importance of planning for crisis or emergency, especially considering the recent global events such as the pandemic and large-scale conflicts. This theme highlights how families were proactive in recognizing the need to prepare for potential disasters, but also encountered the difficulties in planning:

So, we got our son almost eight years ago. Everything turned upside down then, and I stopped even thinking along these lines of crisis preparedness. The crisis was just to make life work. He has some disabilities and other things.

Participants further demonstrated an awareness of the importance of crisis preparedness, having discussed it within the family unit: "There is a barbecue area in the yard. There are probably people who have charcoal somewhere. The first meals can probably be heated in some way." Other potential strategies were considered: "I started looking a bit, because I'm out for a walk with my daughter. So, I started in the nearby area. Looking around—where are the places that might have electricity? IKEA uses solar panels" or "I have a small safe with about a thousand kronas in it. It's my reserve in case there's something. It's not much, a thousand kronas. But in such a situation, cash is king."

There was a notable absence of specific plans. This suggests a gap between theoretical acknowledgment of preparedness and practical implementation. However, it is noteworthy that some participants exhibited proactive behaviors, such as mental strategizing around essential resources like food and shelter: "Yes, that's something we have considered to some extent. Firstly, we have thought about where our nearest shelter is located. And how do we find our way there?" They also contemplated the acquisition of necessary supplies, such as water containers and battery-powered radios. One participant stated:

We've always tried to be a bit prepared at home. We always buy the next size up in winter clothes or shoes for the kids. There are always things at home. We have an extra supply of water at home; it was something I thought was important when I built that house. We've always had food prepared. When you say you're going to manage for a week, we've had that for several years, and we've probably never really thought about it. We just have it."

Additionally, participants demonstrated an understanding of the potential challenges in accessing assistance during emergencies, highlighting the need for self-reliance and tailored municipal support.

Accessibility

The study reveals significant challenges in accessibility for individuals with disabilities during crises. The family members expressed uncertainty regarding wheelchair accessibility to shelters, highlighting a potential barrier to seeking refuge as in this participants case:

I have found out that there are shelters and that they are quite close from here.

However, I don't know if there is a chance to get down there with a heavy and clumsy wheelchair. There are usually stairs and all.

Additionally, evacuation is seen as complicated by a lack of suitable transportation, emphasizing the need for tailored evacuation plans and accessible transportation options for vulnerable populations, especially for the families with children who have multiple disabilities. One family expressed worries about heavy and necessary equipment:

But then one would think that evacuation might be necessary. Like if they come with buses, then you would probably have to help carry him onto the bus. But how do you bring his equipment? He needs to have a wheelchair. Maybe you can bring some things in a backpack. You may not be able to bring everything with you.

One person expressed difficulty as a blind person in navigating new places in an emergency: "There must actually be someone on site; there must be staff who can give us information. What's happening? Where should we go? And show us, physically guide us there. Offer an arm so that we find the right place." The need for practice finding shelter beforehand also was mentioned:

One can't really go around the entire shelter or potential evacuation apartments beforehand and check. It's on-site. Someone needs to take the time on-site to describe what it looks like and perhaps show us around a bit. That's probably it.

Information

When the participants were asked about preparations already taken, all commented on the need for more information and the barriers to accessing information on their situation:

I don't know who to contact to go to the shelter and check. That can, of course, be found out. But we haven't received any information about this either; I have found out by myself. One has to go in and look at the shelter map and such.

Another said: "I would like clear information about shelters. I would like there to be an emergency function regarding medication. That there was an emergency stockpile." Two of the participants had been in contact with the local municipality to find out more and a majority indicated that they had planned with extended family to help in an emergency: "When it comes to crisis and planning specifically, I feel that the crisis information available is very general and targets a very broad audience. For such special groups that we belong to because of (name), we have no clue." Several participants mentioned online networks and communities disseminating information that could be useful in a disaster: "I have a Facebook group with other parents. From there, I get almost all useful information, I would say. It's usually the beginning of something, turning to other parents, because so very few have the same problem." And another observed: "We are entirely dependent on each other in these groups, I would say. There are some parents who have almost dedicated their lives to helping others." One parent shared positive experiences with the municipality's information service:

So, she needs to have it on paper. I must say that the disability services were fantastic during the pandemic times. They actually sent letters with information, and it was in

easy-to-read Swedish. There were even pictures. So, it was like, yes, they understood here. It was excellent information regardless of whether you can speak Swedish or not. Image and text simplicity, the brochure should be distributed to all residents of (City). I am completely convinced it would have been understood differently.

Technology

Several challenges related to technology and healthcare preparedness during crises are highlighted in the material. One of the participants cited this example:

Where do you turn to get electricity? And someone said you have to buy one of these small crank radios. So that you have power. I can't charge her C-PAP, for example.

The breathing machine. It requires much more than a hand-crank generator to work.

Restrictions prevent stockpiling medicine and medical equipment, leaving individuals vulnerable in emergencies. Reliance on medical equipment increases vulnerability in a power outage, made worse by supply chain issues and medicine shortages. One participant described this situation:

She has medical equipment that requires electricity to function. She has a bed with a mattress that is ... yes, exactly. It must have electricity all the time, otherwise it freezes. What do we put her on then? Is it pressure-relieving, like ... yes, and then there's the breathing machine and inhalation that ... It wasn't the phone charging that was the primary concern. But it was like, what the heck do we do with all the stuff?

Communication can be affected when assistive technology fails during power outages. There is a need for safe evacuation spaces equipped with essential medical equipment like breathing aids and tracheotomy suction devices. Some of the families in the study had also bought things like a generator, a stock of food or adult diapers to make sure

there were enough in a crisis. The families demonstrated an awareness of the gaps in availability of support systems for the technology and equipment they need:

I know that healthcare is decentralized in such a way that there should be more healthcare at home. And that includes everything from dialysis to other treatments. And that requires electricity. So, the regions must start thinking, okay, what do we do if it doesn't work?

One parent described how medical equipment is necessary for eating:

He can sometimes eat through his mouth, but most of the time, we administer through a button on his stomach. How are we doing with syringes, tubes, and these buttons? Every three months, we receive a shipment, and we can order what we need. What happens if we can't get hold of them? We've thought about that. There has always been a delivery truck. You go into an app, order, and it gets delivered home.

We can mash food and inject it. It's a backup, but we need syringes, tubes, and this special valve that needs to be changed every three months. You can only get one at a time. On occasion, we've requested an extra one if we're traveling or away somewhere. It's a small balloon filled with water inside the stomach, and if it bursts, you have to give a new one.

Strengths

The importance of a close network was emphasized several times. Family, varied communities, and local cooperation are recognized as essential components of disaster preparedness for people with disabilities and their families:

We have thought about it in a way, you know, we don't know. Now my husband and I live alone. We are both blind. Depending on how easy it is to move around and how easy it is for our relatives to perhaps pick us up or so, it may be that we might gather.

Some other strengths observed includes the development of a family plan for sheltering in place, indicating proactive preparedness measures in the family setting. Informal networks created by parents of children with multiple disabilities emerged as valuable resources for both knowledge and support during crises. These networks, along with social media platforms and communities, facilitated the rapid acquisition of specialized equipment during emergencies, outpacing the efficiency of official channels. One parent stated:

Yes, because I've heard very specific topics and combinations ... perhaps not a large group, but internationally, it becomes a bunch of people who know things. Yes, exactly. Some diagnoses I can imagine, there you probably have worldwide contacts. To get new and the latest research and aids and such that are specifically for that unique diagnosis.

Another participant told of a resource they have used:

For example, there is a Facebook group called "The Button Thread." There, they only discuss matters related to tube feeding and how the button works. There are other groups where they talk about all of life's concerns in general when you have children with disabilities.

These findings show the importance of leveraging informal networks and digital platforms as effective means of support and resource dissemination during emergency situations.

Discussion

In this section, a discussion on the findings is presented. This study focuses on crisis planning among families with disabilities, analyzing their specific obstacles and preparedness requirements.

Awareness

Similar to Chang et al., (2023), the majority of families interviewed for this study had thoughts on how to seek support or be the supporter of their family members during emergencies. This also extended to relatives outside the immediate family unit. The complexity of crisis preparedness attitudes and behaviors within the population that was interviewed showed a recognition of the need to prepare for emergencies, but the difference between acknowledgment and acting was apparent. Participants seem to engage in what could be termed as "passive preparedness" — they had contemplated the idea of readiness, discussed it within their families, and even considered some specific measures such as acquiring water containers and battery-powered radios.

The interview study revealed a variety of attitudes about preparedness within the population. In line with research by Hipper et al. (2018) and Orru et al. (2023), the families prepared for crisis at varied levels. Some individuals or families are proactive, strategizing about essential resources and thinking about practical steps to enhance their readiness. On the other hand, there are those who may be less proactive, only thinking about preparedness when prompted by external factors or discussions within their social circles. This variance underscores the importance of understanding the factors influencing individual preparedness behaviors, which can range from personal beliefs and experiences to socioeconomic status and access to proper information. Importantly, participants expressed awareness of the challenges they may face during emergencies, such as difficulty in accessing assistance and

the need for tailored support from municipal authorities. This awareness reflects a critical aspect of preparedness: understanding one's vulnerabilities and the resources available for mitigation. However, there is also a recognition that individual efforts alone may not be enough, highlighting what Hipper et al. (2018) describes as the need for collaboration between communities and local government agencies to develop comprehensive preparedness plans. While the interviewed families demonstrate varying levels of preparedness engagement, there is a clear need for more focused efforts to bridge the gap between awareness and action. By addressing these gaps, communities could better equip themselves to effectively respond to crises and mitigate the impact of emergencies on both individuals and localities.

Accessibility

The findings highlight the critical issue of accessibility for individuals with disabilities during crisis situations. Participants expressed genuine concerns about whether their wheelchairs would be able to navigate shelters effectively. This uncertainty not only raises questions about the physical infrastructure of shelters but also points to a broader issue of inclusivity and accommodation for diverse needs within emergency preparedness plans. The study by Crawford et al. (2023) mirrors this with experience of family carers expressing concerns about the difficulties to evacuate in a crisis and experiences of inaccessible shelters during actual disaster scenarios. The study reveals the significant challenges faced by individuals with multiple disabilities when it comes to evacuation. Without suitable transportation options, evacuating becomes a daunting task, potentially leaving individuals stranded and exposed to heightened risks during emergencies. This highlights a systemic failure in emergency planning that inadequately considers the needs of those with mobility limitations and multiple disabilities.

These findings can prompt a critical discussion on the need for inclusive emergency preparedness strategies. It is not enough for shelters to merely exist, they must be designed and equipped to accommodate individuals with diverse mobility needs. This includes ensuring wheelchair accessibility, providing accessible transportation options for evacuation, and offering support services tailored to the needs of individuals with disabilities. While these challenges faced by individuals with disabilities during crises highlight broader issues of equity and social justice, access to safe shelter and reliable transportation during emergencies is a basic human right. Yet these findings reveal systemic barriers that prevent individuals with disabilities from exercising that right fully.

Information

Families may need to create channels of communication with healthcare providers and local emergency agencies to ensure rapid assistance during a crisis. The study findings highlight significant gaps in information and clarity regarding emergency preparedness resources and procedures. Chadwick et al. (2022) discuss the lack of accessible COVID-19 information during the pandemic. Participants also reported a lack of information on nearby shelters, hindering their ability to make informed decisions during emergencies. The absence of clear instructions resulted in a lack of practical planning, leaving individuals uncertain about where to seek assistance and what responsibilities fall on which level of government, whether local, regional, or national. This uncertainty made finding answers and solutions to specific questions more difficult, indicating a systemic failure in providing accessible and comprehensive guidance for emergency preparedness. Addressing these gaps is essential to ensuring that individuals can effectively navigate emergencies and access the support they need in times of crisis.

Technology

The intersection of technology and family preparedness for crises shows several critical challenges. First, restrictions on stockpiling medicine and medical equipment impose significant vulnerabilities, leaving individuals reliant on external supply chains during emergencies. As reflected in the research by Lindsay and Hsu (2023), technology and dependence on medical equipment were a significant area of concern. This dependence can become precarious during power outages, when the reliance on medical equipment becomes a problem. Compounding this issue are supply chain disruptions and shortages of essential medications, exacerbating the risks faced by those with medical needs. This issue is also discussed by Crawford et al. (2023); carers closest to the individual with a disability have critical knowledge about the situation and can provide useful solutions to address problems.

The reliance on assistive technology introduces additional complexities. During power outages, communication channels can falter, further isolating individuals and hindering access to essential services and support networks. This insight, shared by Barton-Hulsey et al. (2024) highlights the necessity for robust backup systems and contingency plans to maintain connectivity and communication channels during emergencies. Also important is the need for safe evacuation spaces equipped with specialized medical equipment. Individuals requiring breathing aids or tracheotomy suction devices face heightened risks during evacuations if adequate provisions are not in place. Ensuring the availability of such equipment in evacuation centers is essential to safeguarding the health and well-being of vulnerable populations during crises.

The urgent need for comprehensive emergency planning that addresses technological vulnerabilities in family preparedness is highlighted in this study. Strategies to mitigate the risks include enhancing local stockpiles of medical supplies, implementing backup power

systems for critical medical equipment, and establishing communication protocols to support individuals reliant on assistive technologies during emergencies. By prioritizing these measures, communities can better protect the safety of individuals with medical needs during emergencies.

Strengths

As described in the study by Hamann et al. (2016), the importance of a close network has been emphasized by the participants. Family, varied communities, and local cooperation are recognized as essential components of disaster preparedness for people with disabilities and their families. Informal networks, as discussed by Crawford et al. (2023), are also a resource for carers such as relatives and spouses who may have experience with previous crisis and have knowledge about what worked and what needs improvement. Two of the interviewees who have experience with online networks observe that these share common interests around a specific disability. The virtual communities serve as knowledge-sharing resources and channels of communication that can help with practical issues in a crisis.

Conclusion

The study adds to the body of knowledge around crisis planning and the significance of personalized emergency preparedness and support processes in ensuring the security, health, and well-being of people with disabilities during crises or disasters. Addressing these specific needs and problems can help communities build resilience and respond more effectively to emergencies affecting people with disabilities.

The study's main outcome underscores the importance of representation—ensuring the active participation of people with disabilities in planning processes. Initial investigations reveal a lack of coordination in crisis planning, necessitating a platform or arena for information exchange and practical preparation. The findings also highlight the need for

customized readiness exercises and disaster scenarios for effective engagement. The insights further emphasize a shift from knowledge transmission to actionable readiness and adaptive materials, as well as inclusive involvement.

With a focus on the importance of early engagement in planning, this research can help policymakers, emergency planners, and support organizations identify areas of improvement in crisis preparedness for people with disabilities and their families.

References

- Alexander, D., Gaillard, J. C., & Wisner, B. (2012). Disability and disaster. In *Handbook of hazards and disaster risk reduction* (pp. 413-423). Routledge.
- Barton-Hulsey, A., Boesch, M. C., Chung, Y., Caswell, T., Sonntag, A. M., & Quach, W. (2024). Emergency and disaster preparedness for individuals who use augmentative and alternative communication: A pilot study on supported planning using a toolkit. *American Journal of Speech-Language Pathology*, *33*(1), 16–32.
- Braun, V., & Clarke, V. (2021). One size fits all? What counts as quality practice in (reflexive) thematic analysis? *Qualitative Research in Psychology*, *18*(3), 328–352.
- Clarke, V., & Braun, V. (2013). Successful qualitative research: A practical guide for beginners.
- Chadwick, D., Ågren, K. A., Caton, S., Chiner, E., Danker, J., Gómez-Puerta, M., ... & Wallén, E. F. (2022). Digital inclusion and participation of people with intellectual disabilities during COVID-19: A rapid review and international bricolage. *Journal of Policy and Practice in Intellectual Disabilities*, *19*(3), 242–256.
- Chang, K. Y. J., Villeneuve, M., Crawford, T., Yen, I., Dominey-Howes, D., & Llewellyn, G. (2023). Disaster preparedness, capabilities, and support needs: The lived experience perspectives of people with disability. *Disabilities*, *3*(4), 648–665.
- Crawford, T., Yen, I., Chang, K. Y. J., Llewellyn, G., Dominey-Howes, D., & Villeneuve, M. (2023). How well prepared are we for disaster? The perspectives of informal carers of people with disability. *International Journal of Disaster Risk Reduction*, *93*, 103785.

- Hamann, C. J., Mello, E., Wu, H., Yang, J., Waldron, D., & Ramirez, M. (2016). Disaster preparedness in rural families of children with special health care needs. *Disaster Medicine and Public Health Preparedness*, *10*(2), 225-232.
- Hipper, T. J., Davis, R., Massey, P. M., Turchi, R. M., Lubell, K. M., Pechta, L. E., ... & Chernak, E. (2018). The disaster information needs of families of children with special healthcare needs: A scoping review. *Health Security*, *16*(3), 178–192.
- Lindsay, S., & Hsu, S. (2023). Emergency and disaster preparedness among children and youth with disabilities and chronic conditions, their caregivers and service providers: A scoping review. *Disability and Rehabilitation*, 1-17.
- Orru, K., Klaos, M., Nero, K., Gabel, F., Hansson, S., & Nævestad, T. O. (2023). Imagining and assessing future risks: A dynamic scenario-based social vulnerability analysis framework for disaster planning and response. *Journal of Contingencies and Crisis Management*, *31*(4), 995–1008.



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