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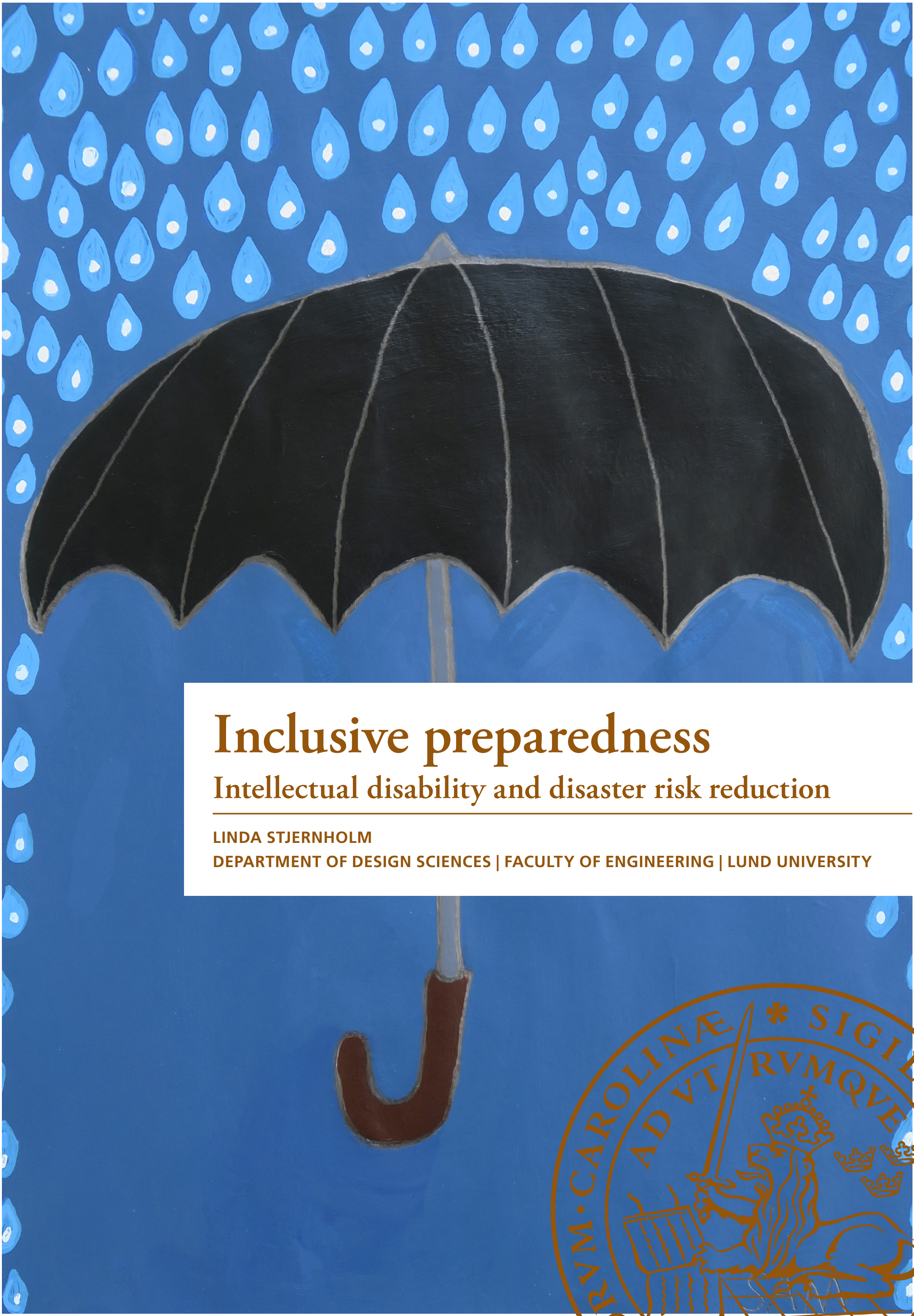

Inclusive preparedness

Intellectual disability and disaster risk reduction

LINDA STJERNHOLM

DEPARTMENT OF DESIGN SCIENCES | FACULTY OF ENGINEERING | LUND UNIVERSITY

Inclusive preparedness: Intellectual disability and disaster risk reduction

Inclusive preparedness

Intellectual disability and disaster risk reduction

Linda Stjernholm

LICENTIATE DISSERTATION

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Abstract:

This licentiate dissertation emerges at the crossroads of critical disability studies and critical disaster studies, with a commitment to justice, equality, and accessibility within the realm of disaster risk reduction (DRR). Its purpose was to develop new insights into strengthening crisis preparedness by actively involving and including people with intellectual disabilities, leveraging their own knowledge and experience. This work rests upon three components: a systematic literature review that explored methods for inclusion of people with disabilities (PWD) into DRR, a disability-inclusive workshop conducted in a municipality in Sweden, and an interview study exploring the family perspective of crisis planning when a member of the family has a disability. The systematic literature review survey's methodologies employed globally in disability inclusive DRR, included workshops, co-designing tools, role-playing, photovoice, and other inclusive practices. By searching the global landscape, this study highlighted the significance of these methodologies toward achieving disability-inclusive DRR. The second component of this research is an account of a disability-inclusive workshop, strategically designed to centre disabled voices and involve different stakeholders. The study involved a workshop in collaboration with disability support services at a municipality in Sweden. The workshop brought together crisis communicators, managers for group homes for people with intellectual disabilities (ID), representatives from disability organizations and PWD of different kinds. To link these two papers, a third study was added to underpin the importance of a family perspective on crisis planning. The family-centred study explored the lived experience of families with a member with disability, highlighting the challenges when it comes to accessibility, technology dependence and information gaps while emphasizing the importance of inclusive, community-supported disaster preparedness initiatives. The overall results showed five dimensions of DRR for people with ID. The first dimension focused on the need to address systemic vulnerabilities that prevent inclusive crisis planning, emphasizing the importance of long-term solutions rather than short term responses. Dimension two points to the value of collaboration and active participation, illustrating how engaging PWD and their support networks enhances preparedness and empowers individuals. Dimension three explored the role of families in bridging gaps to those not closely connected to formal services. Dimension four examined the accessibility challenges PWD faces, revealing the need for tailored information and practices to overcome physical and informational barriers. Finally, dimension five emphasized the importance of community-based solutions and informal networks, which can provide practical resources and support in crisis situations. Together, these dimensions advocate for a more inclusive approach to DRR that recognizes both the unique needs and the contributions of PWD.

Key words: Disability, Crisis planning, Intellectual disabilities, Disaster risk reduction

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Abstract

This licentiate dissertation emerges at the crossroads of critical disability studies and critical disaster studies, with a commitment to justice, equality, and accessibility within the realm of disaster risk reduction (DRR). Its purpose was to develop new insights into strengthening crisis preparedness by actively involving and including people with intellectual disabilities, leveraging their own knowledge and experience.

This work rests upon three components: a systematic literature review that explored methods for inclusion of people with disabilities into DRR, a disability-inclusive workshop conducted in a municipality in Sweden, and an interview study exploring the family perspective of crisis planning when a member of the family has a disability,

The systematic literature review survey's methodologies employed globally in disability inclusive DRR, included workshops, co-designing tools, role-playing, photovoice, and other inclusive practices. By searching the global landscape, this study highlighted the significance of these methodologies toward achieving disability-inclusive DRR.

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To link these two papers, a third study was added to underpin the importance of a family perspective on crisis planning. The family-centred study explored the lived experience of families with a member with disability, highlighting the challenges when it comes to accessibility, technology dependence and information gaps while emphasizing the importance of inclusive, community-supported disaster preparedness initiatives.

This licentiate thesis navigates from the international context, drawing from an overview of global methods for active participation, to a localized workshop in a municipality in Sweden, weaving in local scenarios and knowledge specific to individuals with disabilities. This contextualized approach is deliberate in its intention to bridge the gap between global perspectives and individual experiences, fostering a more inclusive and responsive approach to disaster resilience efforts.

The overall results showed five dimensions of DRR for people with ID:

- Systemic vulnerabilities
- Collaborative participation
- Family as a bridge
- Accessibility barriers
- Community networks

The first dimension focused on the need to address systemic vulnerabilities that prevent inclusive crisis planning, emphasizing the importance of long-term solutions rather than short term responses. Dimension two points to the value of collaboration and active participation, illustrating how engaging PWD and their support networks enhanced preparedness and empowered individuals. Dimension three explored the role of families in bridging gaps to those not closely connected to formal services. Dimension four examined the accessibility challenges PWD faced, revealing the need for tailored information and practices to overcome physical and informational barriers. Finally, dimension five emphasized the importance of community–based solutions and informal networks, which can provide practical resources and support in crisis situations. Together, these dimensions advocated for a more inclusive approach to DRR that recognizes both the unique needs and the contributions of PWD.

Populärvetenskaplig sammanfattning

Personer med intellektuell funktionsnedsättning (IF) är en grupp som ofta exkluderas från samhällets krisberedskap. Deras behov och perspektiv glöms ofta bort, vilket gör dem extra sårbara när kriser och nödsituationer inträffar. Samtidigt har de egna erfarenheter och kunskaper som skulle kunna bidra till att skapa bättre och mer inkluderande lösningar i vår gemensamma krisberedskap. Den här licentiatuppsatsen handlar om hur vi kan förbättra krisberedskapen genom att aktivt inkludera personer med IF och deras närstående i planering och förberedelser inför kris. Forskningen bygger på tre delar: en internationell översikt över metoder för att inkludera personer med funktionsnedsättning i krisberedskap, en workshop i en svensk kommun där personer med funktionsnedsättningar, personal från kommunen och representanter från funktionshinderorganisationer möttes, samt en intervjustudie med familjer som har en medlem med funktionsnedsättning. Genom dessa studier framträder en bild av vilka utmaningar som finns men också vilka möjligheter som uppstår när personer med IF och deras nätverk får vara delaktiga.

Den internationella översikten visade att det fanns flera kreativa sätt att engagera personer med funktionsnedsättningar i krisberedskap. Metoder som workshops, samskapande, fotoprojekt och rollspel har använts med framgång. Metoderna har inte bara ökat delaktigheten för individerna men även lett till en bättre krisplanering som är mer anpassad efter individuella behov. Trots detta är det tydligt att det fortfarande saknas en systematisk inkludering i många länder, däribland Sverige.

I den svenska workshopen deltog personer med olika funktionsnedsättningar, chefer och personal från gruppbostäder, kriskommunikatörer och representanter från funktionshinderorganisationer. Tillsammans arbetade de med krisscenarier för att identifiera hinder och lösningar inom krisberedskap. Resultaten visade tydligt hur viktigt det är att inkludera personer med IF i sådana samtal. Deras perspektiv gav insikter som annars riskerar att förbises, som hur information bör presenteras för att bli tillgänglig och hur viktig personal och närstående är för informationsförmedling i en kris.

Intervjustudien med familjer belyste en annan viktig aspekt: familjens roll som brygga mellan individen och samhället. Flera familjer beskrev utmaningar med otillgänglig information, teknologiberoende och bristande stöd från samhället. De lyfte också behovet av lokala nätverk och informella resurser, särskilt i akuta situationer där formella strukturer inte alltid räcker till. Samtidigt visade deras berättelser att familjer ofta har en stark förmåga att hitta kreativa lösningar och anpassa sig, vilket kan bidra till att utveckla bättre strategier på samhällsnivå.

Resultaten visade på fem viktiga områden inom krisberedskap för personer med IF: resurser och institutionella barriärer, samarbete och delaktighet, att bygga broar, tillgänglighetsbarriärer och vikten av informella och lokala nätverk. Resurser och institutionella barriärer handlade om bristen på långsiktig planering som tog hänsyn till funktionsnedsättningar. Samarbete och delaktighet visade på vad som kan uppnås när personer med IF och deras nätverk aktivt involveras i planeringen. Familjens roll var särskilt viktig eftersom de ofta fungerade som en bro mellan individen och de resurser och information som fanns tillgänglig. Barriärer för tillgänglighet var ett återkommande problem och en oro då information och stöd ofta var utformat utan hänsyn till olika funktionsnedsättningar. Slutligen betonades vikten av lokala nätverk och informella stödstrukturer, som ofta fick fylla luckor där det formella stödet brast.

Den här uppsatsen vill utmana den traditionella synen på personer med IF som passiva mottagare av hjälp under kriser. I stället lyfts de fram som aktiva deltagare med värdefulla perspektiv och erfarenheter. Genom att skapa mer inkluderande processer i krisberedskapsarbetet kan vi inte bara stärka deras egen beredskap utan också bygga ett mer rättvist och motståndskraftigt samhälle.

List of Papers

Paper I

Stjernholm L., Borell J. and Osvalder A-L. (2024) Active participation of people with disabilities in disaster preparedness and contingency work: A systematic literature review of methods, outcomes, and challenges. Under review in *Progress in Disaster Science*.

Paper II

Stjernholm, L., Magnusson, C., Rassmus-Gröhn, K. & Borell, J. (2024) Enhancing Inclusive Crisis Planning: Insights from a Disability-Inclusive Scenario Workshop. *Design for inclusion: Proceedings of the 15th International Conference on Applied Human Factors and Ergonomics (AHFE 2024),* July 24-27, 2024, Université Côte d'Azur, Nice, France. AHFE, Vol. 128. s. 74-81 Published.

Paper III

Stjernholm L. (2024) Navigating Uncertainty: The Family Perspective of Preparing for Crisis with a Disability. *Review of Disability studies: An international Journal*. Accepted for publication.

Author's contribution to the papers

Paper I

Conceptualization, Methodology, Formal analysis, Writing – original draft, Writing – Review & Editing.

Paper II

Conceptualization, Methodology, Formal analysis, Writing – original draft, Writing – Review & Editing.

Paper III

Conceptualization, Methodology, Formal analysis, Writing – original draft, Writing – Review & Editing.

Abbreviations

DRR	Disaster Risk Reduction
DIDRR	Disability Inclusive Disaster Risk Reduction
ID	Intellectual Disability
PWD	People/person with Disability

Introduction

Setting the stage for inclusive disaster risk reduction

In a world increasingly affected by climate change and other crises, those who are most at risk often have the least to say in how to plan, prepare and respond to situations like that (Stough & Kang, 2015). This imbalance perpetuates systems of exclusion, limiting the effectiveness of disaster responses and often leaving behind marginalized groups. Among those groups are individuals with intellectual disabilities (ID), whose voices are frequently overlooked in disaster planning (Stough, 2015). In this context, this research seeks to address these gaps by emphasizing the important role of inclusion in effective disaster risk reduction (DRR) strategies.

Using critical disability studies as a framework, this thesis seeks to challenge the traditional, sometimes paternalistic view that has historically marginalized people with disabilities. At the heart of this perspective is the recognition that individuals with ID should not be passive recipients of help in a crisis but active agents. By centring and focusing on people with lived experience, this thesis aims to shed some light on how structures within DRR could be reimagined to promote more inclusive participation.

Historically, people with disabilities have been underrepresented or neglected in frameworks relating to disaster risk reduction (Alexander, 2015). Critical disaster studies serve as an important analytical lens to question inherent power structures and dynamics that exist in DRR frameworks (Remes et al., 2021). Focusing on the intersections of disability and DRR, this thesis will examine both the vulnerabilities faced by people with ID and their often-over-looked strengths and capacities. In doing so, this thesis aims to offer insights into how DRR practices can be more inclusive and equitable.

Some contexts

People with ID often face compounded marginalization through exclusion, social and economic vulnerability, and stigma (Stough, 2015). Critical disability studies are an interdisciplinary field of research that examines how societal structures, policies and norms define and respond to disability (Meekosha & Shuttleworth, 2009). It challenges medical and traditional views of disability as a personal deficit, emphasizing the role of power, oppression and cultural representations as shaping the experience of disability. It advocates for social justice, accessibility and inclusion while at the same time questioning ableist assumptions and practices in society. Using this lens of critical disability studies, it is possible to explore how this can be mitigated in a disaster risk reduction context by centring disabled voices and adapting methods to be used to lower the threshold into crisis planning for this group. This in turn reframes thinking about intellectual disabilities as an individual problem into understanding the social oppression that creates inaccessibility and limits full participation.

Connecting this to critical disaster studies and DRR, these frameworks can intersect in useful ways. Traditionally, disaster policies and responses frame people with ID as vulnerable and focus on the disability as a source of risk. While this focus on vulnerability addresses real risk, it can also unintentionally reinforce a passive role where capacities, contributions and the knowledge of people with ID are disregarded (Meekosha & Shuttleworth, 2009). Incorporating critical disability studies into DRR recognizes the systemic barriers that contribute to vulnerability rather than only focusing on the individual or the disability. To reframe vulnerability, a more nuanced, inclusive perspective is needed that goes beyond viewing disability as a deficiency.

Rationale and scope

Focusing on people with ID in the context of crisis and disasters is crucial as individuals with ID will often face significant barriers during emergencies (Furukawa et al., 2024), such as difficulties in accessing crisis information and limited communication support. Addressing this offers a chance to strengthen existing support networks and improve the ability to respond effectively in a crisis. By involving individuals with ID in DRR, their unique perspectives are brought to the forefront, which is crucial for creating effective strategies. Their personal experiences can highlight specific challenges and needs that might otherwise be overlooked, leading to more relevant solutions. This engagement not only empowers them but also helps build stronger, more resilient communities in the face of disasters.

While international research provides a foundation for understanding methods for inclusion of PWD, this study was situated in a Swedish context. Recognizing that crisis planning and preparation is different across countries, the focus here was on how Sweden's unique policies and structures can be adapted to better include people with ID, making sure that the findings are relevant to local needs and realities.

Aims and objectives

The aim of this licentiate thesis was to generate new knowledge on how crisis preparedness can be enhanced through the active participation and inclusion of people with ID, drawing on their own experiences and knowledge. By analysing and discussing the results from a literature study and two empirical studies, this thesis contributes to the development of knowledge in the form of different dimensions of inclusive DRR, to empower this group to actively engage in crisis preparedness.

The research questions of this licentiate are:

RQ1: What is the current state of disability inclusion in Sweden's crisis planning system, according to crisis planners and disability organizations?

RQ2: How can meaningful participation of individuals with ID be integrated in DRR strategies?

RQ3: What are the specific ways that people with ID can demonstrate personal agency in DRR and in what ways can this be promoted within the design of DRR initiatives?

A few words on words

I believe that language plays a crucial role in shaping how we understand identity. Different countries and contexts have varying preferences for terminology. In this licentiate thesis, I lean towards using person-first language because it emphasizes individual before disability, in this case intellectual disability. However, I also recognize that identity-first language is important for many people. Embracing their identity as a core part of who they are can promote visibility and pride, especially within marginalized communities. Personal preferences can differ widely, even within the same community, so it is essential for me to honour how individuals want to be identified. I have also noted that the country of origin influences how terms are understood and accepted. Some terminology may not translate well or carry different connotations depending on the historical, social and political context they come from. When it comes to people with ID, I find that person-first works well, so far, in a Swedish context as it is reported as the preferred terminology by disability organizations for people with ID and this is my primary reason for choosing this.

Theoretical framework

This section outlines the theoretical frameworks that guide the exploration of active participation for people with ID in DRR. The research is rooted in critical disability studies, which challenges traditional views of disability and focuses on the social, more than the individual, causes of exclusion. Additionally, critical disaster studies are used as a framework in this research to question existing power structures in disaster management and explore how marginalized groups are impacted. By integrating these perspectives, the research aims to reframe vulnerability and highlight the agency of people with ID. The theory presented here provide a foundation for a more inclusive, equitable approach to DRR practises.

Critical disability studies

Critical disability studies emerged as a response to how disability was framed in medical research and clinical practice. Traditionally, health sciences treated disability as a medical condition to be fixed, but critical disability studies redefined disability as a natural part of the human experience. Beginning in the 1980s, the field grew across many disciplines, such as humanities, social sciences, arts and educational studies, offering a more nuanced understanding of disability. It acknowledged that disability is deeply connected to other social justice issues, such as racism, sexism, colonialism and classism, highlighting a need for an ongoing critical reflection (Garland-Thomson, 2018). Critical disability studies positioned people with disability and their allies as central in driving and shaping theoretical advancement in research. While building on foundational disability studies knowledge, the field addressed contemporary socio-political contexts and systems of oppression (Goodley et al., 2019).

The social model of disability

Traditionally, the meaning of disability has been understood in different ways. Over time, views such as the religious framing of disability as an act of gods will, or a charity-based perspective, were replaced by a medical model that conceptualized disability as an individual impairment in need of correction (Haegele & Hodge, 2016). A critique of the medical model is that it perpetuates negative perceptions of disability by framing it in a deficit-oriented perspective, which influences societal attitudes and interactions with people with disabilities. A response to this developed in the early 1990s with a shift in focus to the transformation of society rather than the individual.

The social model views disability as a product of societal barriers rather than an inherent characteristic of an individual (Oliver et al., 2012 and Barnes, 2019). The focus is redirected from functional limitations of individuals to the environmental, cultural and societal barriers that create disabling experiences. While recognizing the value of individually based interventions, such as medical, educational or perhaps rehabilitative, the model emphasizes the need for a broader systemic change to empower people with disability.

One critique of the social model is that it oversimplifies the experience of disability by only focusing on societal barriers while downplaying the lived realities of people with disabilities and the medical impacts of impairment, such as pain and fatigue (Shakespeare, 2006). The social model has also been critiqued for its Western-centric perspective, which may not consider how disability is understood and experienced in different cultural contexts (Jarman, 2005). Within DRR, these societal barriers can manifest in inaccessible planning or exclusion from decision-making processes as well a lack of recognition of the capacities of people with ID.

Intersectionality

Intersectionality, as described by Davis and Lutz (2023) and Collins and Bilge (2020), examines how multiple, overlapping identities such as gender, race, class and disability interact to shape the individual experience of privilege and oppression. It highlights that social categories do not operate independently but rather intersect to create complex forms of marginalization. Intersectionality allows for a more nuanced understanding of how inequalities are constructed and how intersections can produce unique forms of discrimination.

Both ID and disaster risk involves complex layers of vulnerability. Using the concept of intersectionality is important to acknowledge the layered experiences of people with ID in disaster contexts. Factors like socio-economic status, gender and cultural background intersects with disability to shape the experiences of risk and exclusion in different disaster scenarios.

Ableism

Ableism as a concept, refers to the discrimination and social prejudice against people with disabilities, often framing their experiences as deficits rather than recognizing their value and agency (Campbell, 2012). This perspective is useful in disaster studies, as ableism can lead to strategies in preparation and response that overlook the specific needs of people with disabilities, thereby increasing their vulnerability during an emergency. By critically examining ableism, more inclusive disaster risk reduction strategies can be developed to ensure access to resources and support for all members of a community, regardless of their abilities.

Ableism is also perpetuated when inclusion is framed as a process of integrating those seen as different, rather than dismantling the structures that define them as such. Sara Ahmed's (2012) exploration of inclusion, highlights "how being welcomed is to be positioned as the one who is not at home". In the context of DRR, this frames PWD as external to the norm, needing special invitation or accommodations, while their full integration and the dismantling of ableist structures remains overlooked.

Critical disaster studies

Disaster studies and DRR

Starting with crisis planning and preparation as a form of DRR, this involves creating a structured approach to prepare for and respond to potential crisis like natural hazards or public health crises. Preparedness includes assessing risks and allocating resources, while planning for the protection of individuals and communities. Governments and institutions have the primary responsibilities for emergency planning as well as coordination of local and national responses. Individuals, on the other hand, are encouraged to prepare, by staying informed and keeping necessary supplies to sustain themselves when government help might be delayed. The phases of crisis management include mitigation, which is work aimed at reducing risk made beforehand, preparedness, which is planning what actions and resources to collect, response, which is the direct action taken during active crisis, and finally, recovery which is long-term efforts to restore normalcy (Wisner et al., 2003).

Crisis exercises can range from table-top discussion-based workshops to full-scale formats involving extensive planning and resources. Discussion-based and scenario-driven sessions allow participants to interact in table-top settings without needing real-time or chronological realism (Borell & Eriksson, 2013).

One common tool used in crisis management to prepare, and practice are scenarios. They are hypothetical events designed to test the readiness of individuals and other stakeholders. Common disaster scenarios include floods, wildfires and severe snowstorms, each presenting unique challenges that help improve preparedness plans by allowing participants to learn and assess while simulating crises (Alexander, 2000).

Vulnerability to crisis and disasters have two aspects interlinked, individual and societal. Individual vulnerability refers to factors like age, health and income level, which can affect resilience in emergencies. Societal vulnerability involves broader systemic issues, such as infrastructure, availability of social services, and economic stability, which together impact how well a community can hold up to and recover from a crisis (Kelman, 2020).

Decolonizing approaches and local perspectives

Critical disaster studies examine how cultural and social practices, such as racism and sexism, contribute to an uneven distribution of risk, vulnerability, and disaster impacts (Oliver-Smith, 2022). This approach looks at disasters as not solely caused by natural events but shaped by structural inequalities and social systems. By uncovering underlying power dynamics and practices that create vulnerabilities, this perspective seeks to challenge dominant narratives and promote a more equitable disaster response (Remes et al., 2021).

Critical disaster studies emphasize knowledge and action in DRR by advocating for the integration of grassroots efforts with institutional and scientific approaches (Gaillard & Mercer, 2013). The decolonization perspective of disaster studies focuses on challenging the dominance of western knowledge and practices in understanding and managing disasters. It critiques how Western frameworks often marginalize local knowledge and impose solutions that overlook cultural and contextual differences. The idea is that disasters should not be seen only through Western scientific or institutional lenses but also through the expertise and experience of local communities (Gaillard, 2021). Critical disaster studies challenge the view of disasters as isolated, sudden events. Instead, disasters unfold over time and are rooted in social, economic and structural conditions. Framing disasters as something unexpected often hides the long-standing vulnerabilities and inequalities that make certain communities more at risk. A critical perspective can look beyond the immediate event to understand the broader political, social and historical context that can contribute to disaster risk. This approach encourages a deeper examination of how systemic issues shape the outcome of a disaster (Remes et al., 2021).

Vulnerability

Vulnerability in the context of DRR refers to how susceptible individuals, communities and social systems are to harm from different hazards. An extreme natural event only becomes a disaster when a vulnerable group is exposed (Wisner et al., 2003). The concepts of vulnerability and resilience have been discussed and become nuanced by adding layers of power structures that intersect to impact further on people with disabilities (Kelman, 2020).

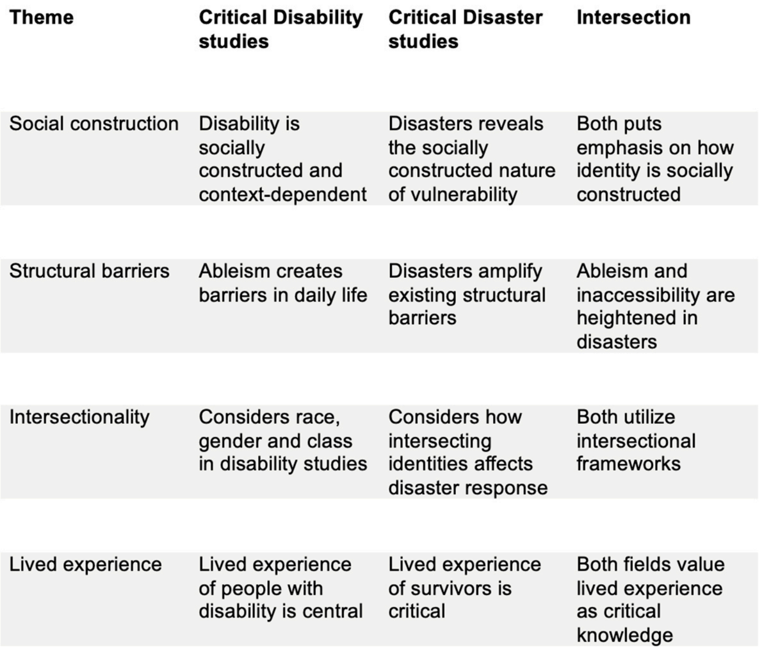
Vulnerability often begins with poverty, as it denies people the ability to make the choices that could improve their resilience in times of crisis. Poverty restricts access to safe living environments, limits purchasing power for essential goods and reduces mobility, particularly when evacuation becomes necessary. When people are poor, they face barriers in reacting effectively to emergencies, even if the early warning provides time to prepare or evacuate (Kelman, 2020). However, vulnerability in a disaster context is complex, as it not only stem from a lack of resources but also from barriers in converting resources into meaningful actions (Ton et al., 2019).

The "tyranny of the present" (White & Haughton, 2017) focuses on immediate disaster response, often neglecting long-term planning, like building accessible shelters and creating evacuation systems that work for people with mobility issues. This short-term thinking increases the vulnerability of people with disabilities, not due to their disability, but because urgent needs drown out future preparation, creating a system that leaves them exposed to danger. Poverty, disability, and the dominance of present concerns intersect, making PWD more vulnerable to future disasters (Kelman, 2020).

Resilience

Resilience concerns how communities can absorb shocks of different kinds, keep essential services running during disasters, and bounce back after the event (Wisner et al., 2003). It is not only about having strong infrastructure, but it also involves social ties and economic stability, which together help communities cope with various challenges. While resilience is often thought of as bouncing back, it also means adapting in ways that make us stronger for future events. Importantly, it should not shift responsibility away from the state or institutions but work alongside efforts to address vulnerabilities like poverty and inequality in a continuous process of adapting and improving responses to crisis (Twigg, 2009).

Table 1: Connections between critical disaster studies and critical disability studies



Theme	Critical Disability studies	Critical Disaster studies	Intersection
Social construction	Disability is socially constructed and context-dependent	Disasters reveals the socially constructed nature of vulnerability	Both puts emphasis on how identity is socially constructed
Structural barriers	Ableism creates barriers in daily life	Disasters amplify existing structural barriers	Ableism and inaccessibility are heightened in disasters
Intersectionality	Considers race, gender and class in disability studies	Considers how intersecting identities affects disaster response	Both utilize intersectional frameworks
Lived experience	Lived experience of people with disability is central	Lived experience of survivors is critical	Both fields value lived experience as critical knowledge

Intellectual disabilities and DRR

Focusing on intellectual disability in DRR planning required a shift in how capacity and vulnerability are understood. Disaster preparedness that addresses cognitive diversity needed tailored communication strategies and support systems (Pyke, & Wilton, 2020). The increasing frequency and severity of climate-related disasters highlighted the critical role of DRR in preparing for events like floods, wildfires and storms. DRR for people with ID remained significantly underdeveloped, despite evidence that this group faced heightened risks during crisis and climate-related emergencies (Watfern & Carnemolla, 2024). This exclusion not only limited awareness but also sidelined people with ID from contributing as advocates for safer, more inclusive climate action and DRR initiatives. A recent study from Japan (Furukawa et al., 2024) reinforced this concern, describing the lack of targeted support and clear communication for people with ID and their caregivers during the Covid-19 pandemic.

Policy analyses further revealed this gap in DRR efforts, where emergency guides lacking in specific considerations for people with ID (Pyke & Wilton, 2020), failed to involve them in planning and relied heavily on individual resilience which was a limited approach for this community. Similar challenges were reported from Costa Rica, where inclusive DRR legislation existed, but was inconsistently applied (Stough, 2015). Across these findings, a clear need emerged for inclusive DRR that actively involve people with ID at all levels, ensuring not only their safety but also their voices in disaster preparedness and response.

Participatory action research and Agenda 2030

Participatory action research and co-design approaches are rooted in the idea of including stakeholders directly in the decision-making process, with a n aim of creating more democratic, relevant and inclusive outcomes. Participatory action research (PAR) as a method, combines research with action, emphasizing collaboration and shared decision-making with the participants throughout the research process. PAR originates from the work of Kurt Lewin, a social psychologist, who in the 1940’s framed action research as a cycle of planning, acting, observing, and reflecting (Lewin, 1946). It has since then evolved into an influential approach that focuses on social change and the empowerment of marginalized groups, making those groups active co-researchers and using their experiences to directly shape the research (Fals-Borda, 1987). In this approach, there is also an educational component that enables the participants to develop skills and an understanding of social issues that impacts them. Through a collaborative “learning by doing”, PAR can strengthen participants' confidence in their own abilities and resources, empowering them to make informed decisions and actively engage in their communities. The method is rooted in principles of equity, where lived experience and knowledge is highly valued, shifting traditional power dynamics of the participant-researcher relationship (Maguire, 1987).

These approaches align well with the concept of a *Ladder of citizen participation* (Arnstein, 1969), as illustrated in Figure 1, which visualizes different levels of control and power that citizens hold in participatory processes. The ladder depicted in the figure illustrates a spectrum from non-participation, where citizens have no influence, to tokenism- a symbolic gesture that can result in presence but without genuine inclusion, and finally to full citizen power, where participants gain actual decision-making power. In the context of DRR, Figure 1 provides a lens to assess the involvement of PWD in participatory research, demonstrating how their participation has often been executed on the lower rungs of the ladder, using PWD as informants or research subjects rather than active decision-makers or co-researchers. This has resulted in interventions that might not have fully addressed their needs or reflected their lived experience.

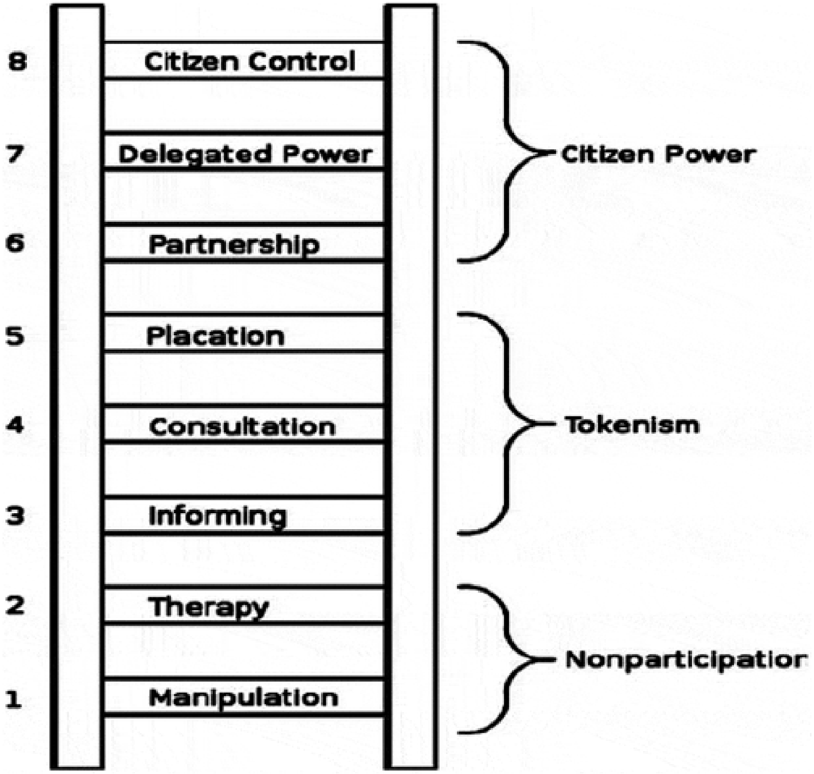


Figure 1: Arnstein's' Ladder of participation (1969)

Agenda 2030's 17 Sustainable Development Goals (SDGs) highlight the critical role of local stakeholder participation, especially from marginalized groups to promote democracy, inclusion, and sustainable development. While the concept of participation varies across different contexts, described as co-creation, user-driven research, and a multitude of other terms, its influence on advancing human rights and improving quality of life is important (Denvall & Iwarsson, 2022).

The agenda 2030 emphasis on participation and inclusion is parallelled in the Sendai Framework for Disaster Risk Reduction (Center, 2015), which calls for the active participation of PWD in DRR efforts. The Sendai Framework mandates the involvement of PWD as stakeholders in decision-making processes to ensure that policies address their specific needs (Stough & Kang, 2015).

Methods

Methodology

The methods used in this research were selected to align with the theoretical frameworks of critical disability studies (Goodley, 2019), critical disaster studies (Oliver-Smith, 2022), the social model of disability (Oliver et al., 2012, and Barnes, 2019), Arnstein's (1969) ladder of participation, and participatory research (Denvall & Iwarsson, 2022). These theories guided both the selection of methods and the way in which the methods were implemented, ensuring a research process that promoted inclusion. The critical disability and disaster studies frameworks shaped the decision to include voices from both crisis planners and disability organisations, as well as families with members that have disabilities. These critical perspectives prioritized methods that would centre the experiences of individuals with disabilities as active contributors. Specifically, qualitative semi-structured interviews (Kvale, 1996), were chosen to directly capture the participants' perspectives on disaster preparedness, structural barriers, and accessibility, echoing the theories' emphasis on examining marginalizing structures and institutional biases. The social model and the concept of ableism (Campbell, 2012) informed how the interview and workshop questions were formulated, focusing on identifying environmental and social barriers instead of seeing disability as an individual deficit. This approach allowed a look into how ableist norms might influence disaster planning and affect individuals with disabilities. Intersectionality (Davis & Lutz, 2023, and Collins & Bilge, 2020), as an analytical framework, supported the choice of using participatory workshops to bring in a range of perspectives. The workshop, in the light of Arnstein's ladder of participation and the principles of PAR, emphasized co-creation and active partnership, aligning with the commitment to empowerment and a genuine engagement with affected communities. The workshop enabled participants to contribute directly to the process, making them active agents in shaping the study's outcomes. The methodological decisions were tied to the study's theoretical foundation, with the goal of highlighting and addressing the social, structural, and intersectional barriers that affect the safety and inclusion of PWD in DRR. A pilot study served as a preliminary investigation that defined and informed the design of the subsequent three studies by identifying key questions and topics from within disability organisations and the municipal crisis planners. These interviews provided a framework for selecting appropriate methods in the three papers presented in this licentiate. In paper one, the systematic review, studies were specifically chosen only if they had an element of active participation, to assess what had been done in the field of disability-inclusive disaster risk reduction. Inclusion alone was not enough; the focus was on active involvement. Paper two, a disability-inclusive workshop was designed to encourage collaboration among diverse stakeholders, using materials adapted to meet the needs of people with ID as well as others. This involved simplifying content and offering visual and sonic versions of the scenario that was being discussed. Finally, paper three, the interview study focused on amplifying the voices of harder to reach groups, specifically young people with multiple disabilities and ID in a home environment.

In this study, triangulation (Flick, 2018) was used to enhance the validity of the findings. Data triangulation was achieved by incorporating multiple participant groups, including crisis planners, disability organizations, and PWD and their families. Methodological triangulation was used by combining a systematic literature review, semi-structured interviews and a participatory workshop. Theoretical triangulation further enriched the analysis by using diverse frameworks such as critical disability studies, critical disaster studies and the social model of disability, establishing a rich understanding of the research questions.

Ethical considerations

Ethical approval for this study was granted by the Swedish ethics review board under approval number 2022-04091-01. The research followed ethical practices regarding confidentiality, protection of personal data and participant well-being. Informed consent was obtained from all participants, ensuring that they understood the nature of the study and its purpose. To achieve this, certain practices were necessary to ensure that this research was conducted in an accessible and ethical manner. This involved adapting consent processes to make information understandable and accessible. Communication methods were tailored to meet individual needs, especially for the participants with ID, the use of easy language and visual aids was crucial.

Pilot study with interviews with disability organizations and municipality crisis planners

The initial interview-study employed qualitative semi-structured interviews (Kvale, 1996) to gather insights from representatives of disability organizations representing individuals with hearing, visual, intellectual, and physical disabilities and crisis planners from different geographical context. It was a conscious decision to choose municipalities that varied in size and place, ensuring both urban, rural and island settings were represented in the material. The semi-structured format was chosen to give flexibility in exploring themes while allowing interviewees to share their experiences in their own words. Unlike structured interviews, which adhere to a strict set of questions, semi-structured interviews enable the interviewer to ask follow-up questions based on the participants' responses. This, more open format can be important as it encourages a more authentic dialogue than more formalized questions do (Kvale, 1996).

A total of nine interviews were conducted with four disability organizations and five municipality and regional crisis planners, using a flexible interview guide to encourage an open dialogue. This method allowed participants to share their experiences and perspectives on how people with disability are considered in crisis planning. The data collected from the interviews were analysed to identify key themes and concepts relevant to the participants´ views. The aim was to uncover gaps in crisis planning regarding the inclusion of people with disability and to highlight the importance of their perspectives in the planning process.

Paper one: Systematic literature review

For the systematic literature review, a structured, step-by step process was followed, based on the PRISMA guidelines (Moher et al., 2015), to ensure that the study could be replicated by others. The process began by defining the study rationale, developing a search strategy and establishing a clear inclusion and exclusion criteria. A preliminary search was conducted using the PICO framework (Population, Intervention, Comparison and Outcomes) to ensure that relevant keywords and concepts were captured in the search (Schardt et al., 2007). To validate and refine the search strategy, a "gold set" of highly relevant articles was identified, which then played a role in fine-tuning the search strings. This iterative refinement of the search strings ensured that the final search was broad enough to capture the relevant studies, but specific enough to exclude irrelevant ones. The search was then carried out in the Web of Science and Scopus databases, yielding 577 articles. The final review included 19 articles, which were subjected to a detailed analysis.

Throughout this process, emphasis was placed on ensuring that studies did not just include people with disabilities but actively involved them in meaningful roles. The use of a structured method and validation process with the gold set enabled the review to capture relevant and rigorous studies in the field of disability inclusive disaster risk reduction. The systematic approach provided an understanding of the existing literature on methods for active participation in disaster risk reduction for people with disabilities and highlighted some gaps that that remain in this area of research. It also provided the basis to conclude that there is a significant gap in research on disability-inclusive disaster risk reduction methods, highlighting the need for more studies and interventions in this area.

Paper two: Disability-inclusive co-creation workshop

As Ollerton (2012) noted, research has often been conducted on people with disabilities, not with them. This limits the depths and relevance of any insights gained. Co-design and co-creation, however, shifts this approach by actively involving participants as collaborators, allowing PWD to contribute their lived experiences and perspectives directly. This collaborative process values participants as experts of their own experiences, enhancing both the design itself as well as the outcomes of the research (Magnusson et al., 2018). Through workshops and other participatory activities, co-design can enable groups to work together, generating ideas, testing out concepts, and developing solutions that are more aligned with the real needs of the users.

The study used a participatory design methodology to explore practical approaches to inclusive crisis planning and mitigation. Central to this was a participatory workshop that involved a collaboration with the municipality's division for disability support services and their networks in the local disability communities. The workshop aimed to engage a diverse group of participants, including individuals with disabilities, crisis communicators, representatives from disability organizations, and municipal personnel. In the planning phase, the recruitment was managed through the established networks of local disability services, resulting in a group comprised of eight municipality representatives and thirteen individuals with physical and cognitive disabilities. In developing the workshop, we adapted principles from co-design, an approach that involved future users or citizens as active contributors in the design process (Sanders & Stappers, 2008). Workshops are a commonly used tool in co-design, facilitating direct interaction with participants and allowing insights to emerge through their unique perspectives and experiences. This approach has shown value in working with PWD, enabling accessible and inclusive design processes (Magnusson et al., 2018). In this study, co-design workshops were tailored specifically for the domain of crisis management involving future users.

In this context, two sets of methods are employed with separate objectives. The methods for conducting the discussion-based participatory workshops and the methods for evaluating the effectiveness of the workshops.

Prior to the workshop, visual materials that included photographs and maps related to local crisis scenarios were prepared. To enhance understanding and meaningful dialogue, real images of past floods in the area, were incorporated, along with discussion questions tailored to elicit responses about short term and long-term concerns during a crisis.

At the workshop, an initial presentation established the context and objectives, supported by visual materials and a short animation to make the scenario accessible to all participants. To ensure a diversity of perspectives, participants were organized into mixed groups at four tables, each equipped with printed materials, discussion questions and note taking supplies. After 30 minutes of small-group discussions, participants convened for a larger group synthesis session, which aimed to distil and share insights.

Following the workshop, the analysis process involved transcribing the recorded sessions, setting up a thematic matrix and categorizing themes from the discussions (Braun & Clarke, 2021). This helped facilitate a deeper understanding of key insights from the participants perspectives on crisis planning.

Paper three: Interview study

In this study, a qualitative approach was adopted to explore how families with members who have a disability engage in crisis planning and preparation. To ensure ethical standards were met, the researcher obtained ethics approval and obtained informed consent from all participants involved in the interviews. The study involved four semi-structured interviews (Kvale, 1996) with families where one or more members had personal experience as a person with a disability or living with a family member with a disability. The participants were selected through informal networks and professional connections within the disability community. The interviews, lasting between 45 to 60 minutes, took place via zoom. The conversations were framed by an interview guide, and each session was recorded and later transcribed using the software Whisperer. For data analysis, the study used Braun and Clarkes six-phase process of reflexive thematic analysis (Braun & Clarke, 2021), which involved coding and interpreting recurring patterns of meaning in the collected data. In the next stage of the thematic analysis, the themes were checked to see how well they fit within each theme and how they relate to each other. Other ways of identifying themes are searching for relevance to the research question or themes that offer surprising or unique insights (Braun & Clarke, 2021). Through this method, key themes were identified: awareness, accessibility, information, technology and strengths. These themes captured some important insights into the challenges and resources that can be involved in crisis planning and preparation for people with disabilities in a family context.

Results

This chapter presents the results from three studies by briefly summarizing the findings and organizing each one into topics. Before that, a summary of the findings from the pilot study will be presented to address research question one. This pilot investigation set the stage for the subsequent research and provides valuable context for the main studies. At the time of writing this thesis in the autumn of 2024, paper one is under review for the *Progress in Disaster Science*, paper two has been published in the *Design for Inclusion, Vol.128, 2024*, as part of the AHFE (Association of Human Factors and Ergonomics) conference proceedings. Paper three has been accepted for publication in the *Review of Disability Studies*.

Pilot study

This licentiate was situated within the larger research project "*From a passive recipient to an active resource in the Swedish crisis and contingency system*" and therefore shared many of the same overarching objectives. In the beginning of the project, a series of 9 interviews were conducted with disability organizations and crisis planners from municipalities across the whole of Sweden. These interviews revealed gaps in how Sweden's crisis planning system addresses the needs of people with disability. Despite a commitment to inclusivity, individuals with disability faced barriers in accessing information, services and support during emergencies. One example from the interviews was the disability organization that reported that, "*going forward, we will need to create crisis action plans that individual users can fill out to map vulnerabilities and develop informational materials for both the users themselves and the assistance providers"*. One disability organization for people with ID asked for more support, *"staff and residents (of group homes) need guidance and training in digital tools to access information and prevent isolation"*. The same organization also reported that, *"early on in the pandemic, we created a film about the crisis because it is a good medium for providing information to this specific target group"*.

Disability organizations have had to step in and develop independent solutions to adapt crisis information for their members, highlighting a lack of systemic support. Key issues such as digital exclusion, inaccessible warning systems, and inadequate crisis communication strategies, were disproportionately affecting those with sensory, cognitive, or physical disability. The absence of clear and accessible information left people with disability vulnerable during crisis and a lack of standardized approach to identifying and localizing individuals who needed extra support in emergencies.

While the interviews with the disability organisations highlighted a lack of inclusion, the perspective of the crisis planners showed their challenges as multifaceted. They acknowledged the critical importance of inclusion in their strategies but cited a lack of resources as a significant barrier to effectively working with more inclusive practices. They also recognized the need for a variety of communication channels to reach different populations, *"many different channels, postcards sent home, in-person meetings, screens on public transport, large signs at the supermarket and radio segments"* but logistical barriers, especially in rural or geographically more complex regions, made it difficult to ensure that people with disability received support in time. A representative from a municipality that consists of many islands stated that, *"the islands can be harder to reach in a crisis, depending on which public service is affected"*.

The smaller municipalities reported an advantage in being able to locate and identify individuals that might need assistance, "The municipality is so small that we have personal knowledge of everyone. That is, the social services manager has personal knowledge to draw from". Additionally, a reliance on digital tools, while beneficial to many, further marginalized those who lacked digital literacy or access to technology. As one of the interviewed crisis planners said, "Perhaps digital solutions are not always useful, as in a crisis, both electricity and mobile coverage may be lost".

Summary of results from the studies

Paper 1: Active Participation of People with Disabilities in Disaster Preparedness and Contingency Work: A Systematic Literature Review on Methods, Outcomes, and Challenges

The systematic review revealed that collaborative approaches significantly improve community networks and facilitate cooperation between DRR personnel and PWD. Positive outcomes include capacity building, empowerment, and increased knowledge about DRR, as active participation enabled PWD to gain valuable knowledge through for example peer-learning. Various methods were employed across the studies, such as workshops, focus groups and photovoice, with some integrating PWD from an early stage in the research process while others involved them at later stages. These active participatory methods, including co-creation and co-production, played a crucial role in engaging PWD in disaster preparedness efforts. The most prominent topics from the results are presented below.

The strengths of collaborative approaches

Collaborative methods demonstrated significant benefits in building community networks and promoting cooperation between DRR personnel and PWD. The review highlighted how increased engagement led to greater empowerment and knowledge among PWD when it comes to DRR practices. Peer learning emerged as an effective strategy for building capacity, when individuals was given the opportunity to share insights and experiences.

Challenges identified

Despite the positive outcomes, several challenges were noted. Communication barriers, particularly related to differences in spoken and sign languages created barriers in effective dialogue among participants and researchers. Negative stereotypes about what roles PWD can take in DRR and DRR decision making persisted, creating additional barriers even thought there were improvements in understanding between DRR personnel and PWD and their organizations.

Resource investments and exclusions

The methods employed were often time-consuming and costly, needing significant financial resources for accessibility measures, such as sign language translation. This posed challenges for effective implementation and limited the feasibility of collaboration. Some groups, such as individuals with sensory sensitivities or chronic illnesses, were inadvertently excluded from participation, and selection bias sometimes narrowed the diversity of participants involved in the studies.

Call for further research

The review highlighted the need for more research focused on disability-inclusive DRR. Given the relatively small existing body of work on this important topic, further studies are essential to develop tailored strategies that improve inclusion and effectiveness in DRR efforts for and with PWD.

The systematic review also revealed a significant gap in research on disaster risk reduction involving people with ID, as many of the studies focused on sensory or physical impairments. This underrepresentation highlights the need to better understand how to engage people with ID in meaningful ways during crisis planning and response. To address this gap, the next study involved a disability-inclusive co-creation workshop, designed to actively involve participants with ID. This workshop aimed to explore how inclusive methods could support their participation in disaster risk reduction, ensuring their needs and capabilities are better represented.

Paper 2: Enhancing Inclusive Crisis Planning: Insights from a Disability-Inclusive Scenario Workshop

In the second study, a disability-inclusive workshop was conducted to explore crisis preparedness and response, with a focus on engaging participants with lived experience of disability as well as personnel from the municipality's division for disability services. The workshop facilitated active collaboration among stakeholders, allowing them to collectively address a crisis scenario while engaging in meaningful knowledge exchange. This learning opportunity highlighted some key issues, with participants finding value in the local context of the scenario, which connected closely to their own lived realities.

Knowledge exchange and practical insights

The workshop revealed that participants benefited from a tangible, hands-on-experience using images and maps as well as easy-read discussion questions on each table. It was emphasized that distributing information such as brochures, was insufficient for developing real competence in crisis preparedness. Instead, practicing real-world scenarios, such as navigating to the nearest shelter or handling unfamiliar equipment related to crisis, was seen as more important for building capability. Challenges related to maintaining preparedness kits were also discussed, particularly for individuals reliant on medications that is difficult to stockpile in advance due to restrictions.

The role of personnel and accessibility

Participants with ID mentioned the importance of support personnel, especially those working at daily activity centres or group homes, recognizing their critical role in a crisis. The workshop highlighted how personnel could serve as a key resource for individuals with ID, with comments like "I would ask the personnel" underscoring their reliance on this support network. The municipality was already, to some extent addressing accessibility issues, having collaborated with user organizations during the Covid 19 pandemic to produce accessible information, but gaps in execution and follow up were noted, with some tasks falling through the cracks.

Staff feedback and insights

In a follow-up survey, 6 out of 8 employees from the municipality reported that the workshop generated new insights and was a valuable activity for their future work in crisis preparedness. This highlights the workshop's effectiveness in boosting awareness and preparedness among municipal staff while creating a deeper understanding for the needs and capacities of PWD in crisis scenarios.

Reaching the unconnected and overlooked

A significant challenge was how to reach individuals not already connected to the disability services of the municipality. Many PWD who manage well during normal circumstances may require additional support during crisis. This remains an unsolved issue, as these individuals or families can be difficult to identify and assist without established connections to municipal or care services.

The results from this workshop highlighted the importance of practical, scenario-based learning and the need for continuous improvement in accessibility and support mechanisms for PWD, especially in crisis scenarios. In connection to this, the importance of having stakeholders of different kinds engaged at the same table proved very useful. This second study also gave clues on the difficulty of reaching PWD not connected to daily activity centres, group homes or other programmes connected to the municipality's services. Those PWD who manage most things independently, with family or with at-home assistance, who may need extra help during a crisis. Building on this, the next study explored the family perspective, how families play an important role in bridging gaps in crisis preparedness and addressed the critical issue of providing a platform for knowledge sharing outside the formal disability service system.

Paper 3: Navigating Uncertainty: The family perspective of preparing for crisis with a disability

The third study explored the family perspective of crisis preparedness, focusing on PWD who live in a family setting outside formal care systems. Five themes or topics emerged: awareness of crisis planning, information shortages, accessibility challenges, technology utilization, and informal support networks. While families demonstrated awareness of the need for crisis planning, practical implementation or action were limited. Challenges related to accessibility, information, and technology use were frequently discussed, highlighting the complexities faced by families when preparing for emergencies.

Awareness of crisis preparedness

Families in the study expressed a clear awareness of the need for crisis planning particularly considering recent global events such as conflicts and the pandemic. Although participants acknowledged the importance of preparation, many admitted that daily challenges often overshadowed proactive crisis planning. Several families had thought about potential strategies, such as finding local resources like shelters or considering the logistics of obtaining emergency supplies. However, there was a noticeable gap between recognizing the need for preparedness and taking concrete actions to ensure readiness.

Information shortages and gaps

The study revealed significant gaps in the availability of crisis information tailored to the specific needs of PWD and their families. While some participants had reached out to local municipalities for guidance, most relied on informal networks or online communities to share and obtain useful information. Families highlighted the general nature of most public crisis communication, which often failed to address the unique needs of vulnerable populations.

Accessibility challenges

Accessibility during emergencies was a major concern for families with a member that had a disability. Potential barriers to shelters were pointed out, particularly for wheelchair users or those with mobility limitations, emphasizing the need for evacuation plans tailored to their needs. Families also raised concerns about transporting essential medical equipment during evacuations and the difficulties individuals with for example ID might face in navigating new environments during a crisis. One participant, for example, expressed how difficult it would be for a blind person to reach a shelter without on-site assistance.

Technology and medical equipment

Families expressed concerns about the challenges of relying on technology and medical equipment during emergencies and crisis, particularly in situations involving power outages or supply chain disruptions. Participants noted that many essential devices, such as breathing machines require electricity and the stockpiling of for example feeding tubes materials was often restricted by law. Families voiced the need for better planning and an infrastructure in place to support PWD who depend on these technologies, as well as contingency plans to ensure continuous access to necessary equipment during crisis.

Informal support networks

One of the reported strengths from the participants in the study was the emphasis on informal support networks, which proved invaluable for family's navigating crisis. Social media groups, especially those for parents of children with multiple disabilities, emerged as key sources of information and resources. These online communities allowed families to share advice, coordinate the acquisition of specialized equipment, and offer emotional support in ways that often was faster than official channels. The strong reliance on these informal networks demonstrated how families had adapted to the lack of formal support by creating their own systems of mutual aid.

Discussion

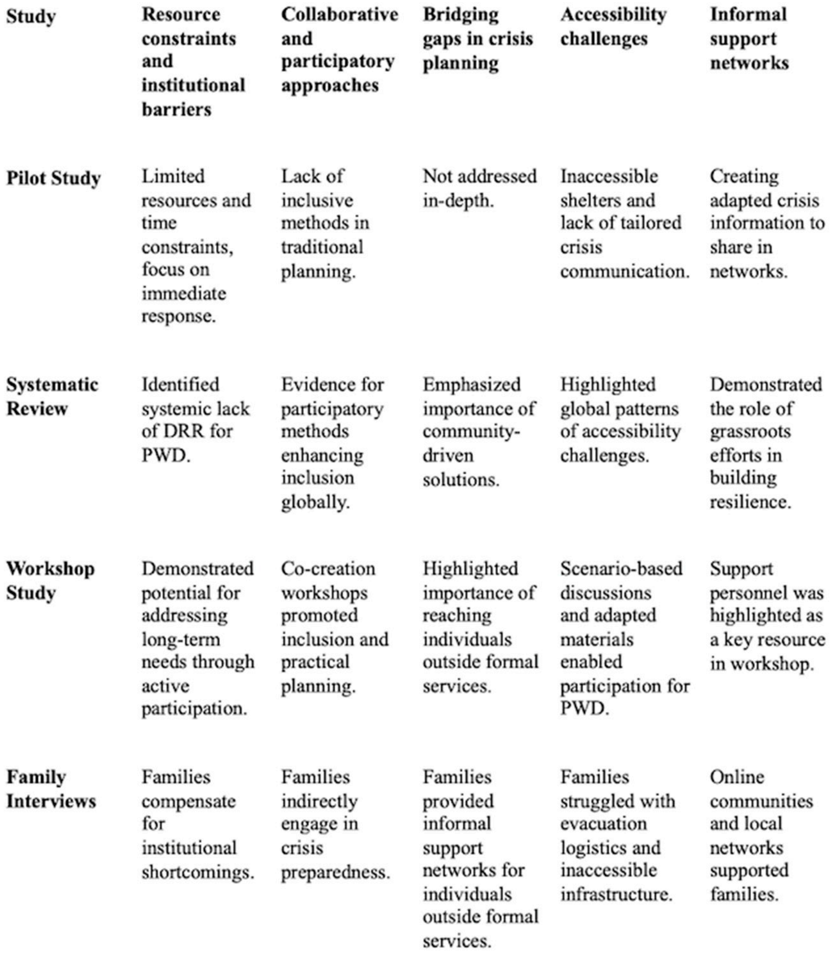
The purpose of this licentiate thesis was to generate new knowledge on enhancing crisis preparedness through active participation and inclusion of people with ID, drawing directly from their experience and insights to inform more inclusive practices in DRR.

The discussion applied the theoretical frameworks of critical disaster and disability studies, the social model of disability, ableism, intersectionality, and participatory action research, integrating each of these to analyse the findings in relation to previous research literature. In structuring the discussion around five key dimensions of inclusive crisis planning, the aim was to synthesize the main findings in a way that captured the complexity and interconnectedness of inclusive preparedness for PWD. These dimensions emerged through a thorough analysis of the results from each included paper, allowing the identification of recurring themes and critical areas that required attention. By categorizing the findings into these dimensions, the discussion could address the various systemic, social and practical aspects of crisis planning for people with ID. Each dimension examined reflected how systemic, structural, and social factors impact the inclusion of people with ID in crisis planning. The following sections address five dimensions of inclusive crisis planning, providing a view of both barriers and potential avenues for more inclusive practices in DRR.

Five dimensions of inclusive crisis planning

To link the insights from each study and connect them to the research questions, the following section will discuss five dimensions of inclusive crisis planning for people with ID. Table 2 shows how the dimensions emerged from the results of the studies.

Table 2: A brief summary of the key findings from each study that contributed to the dimension.



Study	Resource constraints and institutional barriers	Collaborative and participatory approaches	Bridging gaps in crisis planning	Accessibility challenges	Informal support networks
Pilot Study	Limited resources and time constraints, focus on immediate response.	Lack of inclusive methods in traditional planning.	Not addressed in-depth.	Inaccessible shelters and lack of tailored crisis communication.	Creating adapted crisis information to share in networks.
Systematic Review	Identified systemic lack of DRR for PWD.	Evidence for participatory methods enhancing inclusion globally.	Emphasized importance of community-driven solutions.	Highlighted global patterns of accessibility challenges.	Demonstrated the role of grassroots efforts in building resilience.
Workshop Study	Demonstrated potential for addressing long-term needs through active participation.	Co-creation workshops promoted inclusion and practical planning.	Highlighted importance of reaching individuals outside formal services.	Scenario-based discussions and adapted materials enabled participation for PWD.	Support personnel was highlighted as a key resource in workshop.
Family Interviews	Families compensate for institutional shortcomings.	Families indirectly engage in crisis preparedness.	Families provided informal support networks for individuals outside formal services.	Families struggled with evacuation logistics and inaccessible infrastructure.	Online communities and local networks supported families.

Resource constraints and institutional barriers in inclusive crisis planning

The first dimension addressed resource constraints and institutional barriers that restricted inclusive crisis planning for PWD. Insights from the pilot study indicated that the crisis planners interviewed faced challenges in incorporating inclusive methods due to limited time and funding. Although the importance of inclusion was recognized, immediate demands often took priority over more pro-active strategies to improve accessibility. From a critical disability studies perspective, these limitations emphasized how power structures and institutional hierarchies shaped the prioritization of immediate crisis response over long-term strategies to reduce vulnerability. This connected to the concept of the “tyranny of the present” (White & Haughton, 2017) where attention remained focused on the immediate crisis response, neglecting other planning efforts like building accessible shelters or creating evacuation systems for people with mobility issues. This short-term thinking increased the vulnerability of PWD, as critical needs were consistently overlooked. Framing disasters as unexpected events also concealed long-standing vulnerabilities and inequalities that placed certain communities, including PWD, at greater risk. By focusing on the crisis at hand, planners often missed the broader social, political and historical contexts that contributed to disaster risk, as noted in the critical disaster studies framework by Remes et al., (2021). A critical perspective in this context encouraged looking beyond the immediate event to understand how systemic issues, such as underfunded services or inaccessible infrastructure, affected the impact on vulnerable groups. These resource constraints and institutional barriers reinforced existing inequalities and excluded PWD from planning and response efforts.

The insights from the pilot study were echoed in paper 2, which demonstrated how practical, scenario-based approaches could bridge some of these gaps. The workshop highlighted the importance of actively involving PWD in collaborative planning, showing that hands-on engagement led to more effective strategies that addressed both the immediate and the more long-term needs in crisis planning. Also connected to this, paper 3 illustrated how families adapted in the absence of proper institutional support, highlighting the critical role they played in crisis preparedness. Together, these studies underscored the complex interplay between institutional limitations and the need for a meaningful involvement of PWD in crisis planning and response efforts.

The role of collaborative and participatory approaches

The second dimension emphasized the important role of collaboration and active participation in crisis planning for PWD. Both insights from the systematic review and the workshop study highlighted how participatory methods, such as scenario workshops, peer learning, and co-creation enhanced crisis planning outcomes. By directly involving PWD and their support systems, these approaches promoted a deeper understanding of the needs and challenges, as well as strengths and capabilities of these individuals. Involving PWD in crisis planning not only reflected participatory action research principles but also empowered these individuals as agents in their own preparedness. This approach challenged ableist assumptions that depicted PWD as recipients of assistance, positioning them instead as knowledgeable contributors to planning processes (Meekosha & Shuttleworth, 2009). As reflected in Ton et al., (2019) focusing on the capabilities of PWD helped with understanding the disaster risks this group is facing.

In the workshop study, participants engaged in discussions and collaboratively addressed crisis scenarios, resulting in improved knowledge exchange and resource sharing. Such participatory methods aligned with the findings of the systematic review, which highlighted the importance of engaging diverse community stakeholders in DRR practices. By promoting collaboration between DRR personnel, PWD, and their local communities, these approaches effectively addressed the institutional barriers identified in the pilot study.

The pilot study illustrated the lack of inclusive methods in crisis planning, revealing how traditional methods often overlooked the specific needs of PWD. In contrast, the workshop study demonstrated that practical, hands-on engagement could help bridge these gaps, empowering PWD to contribute in a meaningful way to their own crisis preparedness. This active participation was also supported by the idea that grassroots efforts in DRR are important as they integrate local knowledge with institutional frameworks (Gaillard & Mercer, 2013). The critical disability perspective emphasized how collaboration dismantled traditional hierarchies, promoting a more equal distribution of influence within DRR practices.

Critical disability studies offered a valuable framework for addressing research question 2, focusing on how people with ID could achieve meaningful participation in DRR strategies. This perspective addressed how societal structures, norms and policies shaped the experience of disability while challenging views that framed disability as a personal deficit (Jarman, 2005). Instead, it focused on the roles of power and oppression (Meekosha & Shuttleworth, 2009). By centring the voices of people with intellectual disability in the workshop, the lens of critical disability studies helped identify what barriers and marginalization they faced. This was facilitated by adapting the materials and methods to make sure that their active participation was possible. This also meant recognizing what Stough (2015) described as compounded marginalization that could be a reason some people could not attend at all due to social, economic or family obligations.

For individuals with ID and other cognitive disabilities, it is important to recognize that some may need more time and support to provide their input. The findings from the workshop demonstrated that when disaster preparedness considered cognitive diversity, it required clear communication strategies and support systems to allow participants to engage meaningfully in the planning process. This corresponds with the conclusions of Pyke & Wilton (2020), which emphasized the importance of such considerations in the planning process.

Bridging gaps in crisis planning for people less connected to formal services

This dimension highlighted the challenges of reaching some PWD who were not part of formal services like group homes or daily activity centres. This dimension addressed research question 2 by showing how informal support and community-based approaches could enhance the meaningful participation of individuals with ID, particularly by way involving their families or next of kin. By filling gaps left by formal services, these strategies demonstrated how PWD and their families took proactive roles in crisis preparedness, bridging institutional shortcomings and contributing to DRR efforts. Families played a crucial role in supporting PWD during crises, especially for those living independently or receiving at home assistance.

While these families recognized the importance of crisis preparedness, they reported significant barriers to receiving information and resources. They frequently described feeling excluded from official information channels and resources, which added to their difficulty in preparing for crisis. When information was offered, it often seemed not to consider their special circumstances. This reflected the broader issue of ableism, described by Cambell (2012) as the discrimination or prejudice against PWD, often resulting in the devaluation of their experiences and exclusion from opportunities and society at large. Critical disability studies, as Goodley et al., (2019) emphasized, foregrounds the socio-political contexts and systems of oppression that perpetuated such exclusions. When it came to crisis information, ableism manifested as information tailored only to the able-bodied norm, neglecting the specific needs and perspectives of PWD. This in turn resulted in crisis communication and preparedness strategies overlooking or marginalizing families of people with disabilities, leaving them feeling excluded from vital information, which in turn increased their vulnerability during emergencies. The lack of targeted communication and other forms of support for people with ID and their families during crisis was heightened during recent global crises. Furukawa et al. (2024) highlighted the disproportionate challenges faced by people with ID in Japan during the Covid-19 pandemic, partly due to communication failures and insufficient support systems for caregivers. Similarly, Watfern and Carnemolla (2024) argued that climate-related disasters such as wildfires and floods showed the need for inclusive DRR practises. Their work pointed to the heightened vulnerabilities of people with ID during such crisis and the gap in current preparedness initiatives, which was mirrored in the interviews with the families and their concerns about being disconnected from the official crisis planning systems.

This disconnect not only affected the family's preparedness but also highlighted the need for resilience within communities. A resilient community needed both strong infrastructure and strong social ties and economic stability (Twigg, 2009). In this context, community-based solutions emerged as important strategies for bridging the gap in crisis preparedness. By encouraging collaboration and action in the community, the families own solutions enhanced overall resilience in times of crisis. Ultimately, addressing the unique challenges faced by these families proved to be an essential strategy for building an inclusive disaster planning framework that empowered all PWD to participate meaningfully in crisis planning.

Accessibility challenges in crisis preparedness

Dimension four focused on accessibility challenges and examined the physical, technological and informational barriers faced by PWD in crisis planning and emergencies. Informed by the social model of disability, this dimension highlighted how inaccessible infrastructure and information systems in crisis planning further marginalized PWD. Rather than viewing this issue as an intrinsic limitation, the social model interpreted these as barriers imposed by unaccommodating societal structures (Barnes, 2019). This also reflected the intersectional perspective, where the compounded marginalization was a result of overlapping systems of oppression that overlooked the distinct needs of PWD (Davis & Lutz, 2023). In paper 3, the family perspective highlighted practical challenges such as reaching and accessing shelters, transporting essential, and heavy medical equipment in an evacuation, and using technology during crisis, which might include power-outages. These findings were supported by the observations of Collins (2023), who argued that accessibility must be considered not in isolation but in relation to other intersecting factors such as socio-economic status or care-giving dynamics. One aspect of this was that the families' caregiving roles during crisis often intersected with systemic inaccessibility to further increase the overall vulnerability of the family. Inaccessible shelters, for example, were a consequence of a system that failed to account for mobility limitations, instead of being an inherent limitation of the PWD themselves. In the workshop study, this was reinforced by demonstrating how scenario-based discussions could enable participation for people with ID if the workshop was adapted to their needs, removing barriers that other workshops might have put imposed. This connected to the perspective of Pyke & Wilton (2020), who advocated for planning practices that accommodated diverse needs and Goodley et al. (2019) who recognized the expertise of lived experience. Through this lens, the findings illustrated how adapting resources to the needs of PWD strengthened their agency and autonomy within DRR frameworks. Additionally, the use of practical and personal experiences using a real scenario, familiar to all participants, enabled knowledge generation rooted in lived experience.

Informal support networks and community-based solutions

The fifth dimension focused on the role of informal support networks and community-based solutions in crisis preparedness for PWD, as highlighted in the interview study with families. Families reported that online communities connecting others in similar situations provided essential resources in times of need. These networks often responded faster than formal institutions, offering emotional support, practical advice and real-time information sharing. This responds to what Ton et al., (2019) describes as not a lack of resources but rather barriers to converting those resources into meaningful actions or useful support. Informal networks also allowed families to exchange resources like specialized equipment and emergency tips. This sentiment was again echoed by Twigg (2009), who connected resilience to social ties and informal networks, providing essential support and resources for the families in the study.

The workshop study contributed to this dimension by emphasizing the role of the support personnel at daily activity centres as key resources during a crisis, especially when it came to information and advice for people with ID. This reinforced the importance of informal networks, even when they were within formal structures, but also shone a light on vulnerabilities created by this reliance. The systematic review further demonstrated how community-based participation strengthened resilience, showing that these grassroots efforts enhanced crisis response capacity. Incorporating their insights and experiences into official crisis planning aligns with Goodley et al.´s (2019) call for a transformative approach to actively address systems of exclusion while empowering marginalized groups.

Incorporating informal networks into formal DRR strategies could have ensured more inclusive preparedness planning for vulnerable populations. This dimension addressed both research question 2 and 3, offering solutions for integrating PWD and promoting their personal agency within crisis planning frameworks. In DRR, the language of inclusion often positioned PWD as outside the norm, requiring special accommodations rather than being integrated into standard planning. This reflected Ahmed's critique (2012) where inclusion became a gesture that reinforced marginalization, obscuring the structural changes necessary to address the needs of PWD in times of crisis. Integrating informal networks into more formal DRR strategies could have shifted the narrative of inclusion for PWD from outsider status to active participants, creating a more equitable crisis planning.

Ethics discussion

Research involving vulnerable populations, such as people with ID, call for careful attention to ethical principles to ensure that participants are protected and respected. In the context of this study, ethical considerations were central to the processes involving all participants, but especially when people with ID were involved. This was manifested in several practises such as making sure informed consent was obtained in a manner that was accessible to the participants. This approach empowered participants to make informed decisions about their involvement, ensuring that their autonomy was respected in the research process. A different kind of ethical consideration that shaped the research throughout the process was the awareness that discussing crises and disasters might have an emotional and psychological impact on the participants and their well-being. The research team members involved in the workshop and interviews were careful to inform participants that they could take breaks or stop at any time. Another key ethical concern was reflexivity. The research team were aware that issues such as ableism could potentially shape the research process. This was helped by ensuring that the voices of PWD and their families were central in shaping the findings but also acknowledging that participants with ID might face barriers to engaging fully in research.

Conclusions

The overall purpose of this licentiate thesis was to advance knowledge on how crisis preparedness can be strengthened by actively involving people with ID, drawing directly from their experiences and insights to inform inclusive practices. The study emphasized the need for a shift from tokenistic inclusion to meaningful participation, as conceptualized in Arnstein's Ladder of Citizen Participation (1969), showing the importance of collaboration and empowerment in decision-making processes.

This research explored three key questions on disability inclusion in Sweden's crisis planning system, with a specific focus on people with ID. Through the combined insights of the pilot study, the systematic review, the workshop study and the interview study, this research examined both the current level of inclusion and strategies to enable meaningful participation for people with ID and methods to enable their personal agency within DRR initiatives.

Current state of disability inclusion in Sweden's crisis planning system

The findings revealed substantial gaps in Sweden's crisis planning system, influenced by resource constraints, institutional barriers and a lack of inclusive frameworks. Crisis planners faced significant challenges due to limited time, funding, and a focus on immediate crisis response, often sidelining the needs of people with disabilities. This short-term focus, termed the "tyranny of the present" (White & Haughton, 2017) frequently disregarded the long-term strategies necessary to support PWD in emergencies, increasing the vulnerabilities of PWD during emergencies. From a critical disability studies perspective, this short-term focus highlights how systemic ableism marginalizes PWD (Campbell, 2009), perpetuating their exclusion from crisis planning processes. However, the research found that practical, scenario-based approaches, such as those in the workshop study, can address some of those gaps. By involving PWD directly, these approaches begin to address both immediate and long-tern needs, suggesting a way forward for a more effective crisis planning that uses inclusivity as a core principle. These approaches align with participatory design principles (Sanders & Stappers, 2008), by creating opportunities for meaningful involvement and centring the lived experience of PWD.

Integrating meaningful participation for people with ID in DRR.

The study identified participatory and community-centred methods as essential for creating meaningful engagement of people with ID in DRR. Collaborative, scenario-based activities proved effective in the workshop setting, where PWD were actively involved in problem-solving exercises, enhancing understanding among the participating stakeholders. Echoing Ollerton's (2012) critique of traditional research methods that can exclude PWD from decision-making processes, advocating instead for co-creation and a shared agency. The integration of critical disability studies highlighted how societal norms, policies and structural barriers contributed to exclusion and reinforced the importance of adaptive communication and support for cognitive diversity. The research also illustrated that formal crisis planning benefits when supplemented by informal support networks, especially for those less connected to formal services, such as group homes. Families and community members, when integrated into crisis planning, offered valuable grassroots insights that traditional DRR strategies might have overlooked, contributing to a more resilient and inclusive framework.

Promoting personal agency for people with ID in DRR initiatives

This research highlighted the role of informal networks in fostering agencies for people with ID within DRR initiatives. Families, peer networks, and community support systems provide critical assistance, particularly during emergencies, where official information and resources may be insufficient. The findings highlighted that while formal institutions were integral, PWD and their families frequently relied on informal, community-based solutions for practical guidance, equipment sharing and emotional support.

Garland-Thomson (2017) advocated for systems to recognize the lived experience of PWD, this is reflected in how informal networks can play a central role in official DRR strategies to empower PWD and promote active participation during crisis.

Final reflections, limitations and future research

This study emphasized the need for a dual approach to inclusive crisis planning, enhancing formal institutional support to create more inclusive practices to meet the specific needs of PWD, while recognizing the vital role of informal networks in empowering individuals and promoting resilience. By addressing these findings, Sweden's crisis planning system can move towards a more inclusive and equitable framework that actively prepares and engages all individuals to manage and navigate crisis with autonomy and dignity.

The research has some limitations that should be acknowledged. Most importantly, while the study focused on individuals with intellectual disability, the findings could not fully capture the diversity of experiences within this group, especially considering the varying levels of support needs, socio-economic contexts and geographic locations of this group. Related to this, the study was heavily situated in a Swedish context, which may limit the generalizability of the findings to other countries or cultural settings. Finally, the inclusion of family members and caregivers provided valuable insights, but their perspectives may have unintentionally overshadowed the voices of individuals with intellectual disabilities themselves.

A suggestion for future research within this area is to include a larger and more diverse participant base, especially people with varying support needs and backgrounds, to capture a range of experiences. Further studies could also investigate the intersections with other factors, such as gender and ethnicity, to explore additional layers of vulnerability and resilience.

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Inclusive preparedness

This dissertation explored how to enhance crisis preparedness for people with intellectual disabilities by actively involving them and their families in the planning process. The research was built on three studies: an international systematic review of inclusive crisis planning methods, a co-creation workshop in a Swedish municipality with people with disabilities, their support networks, and crisis planners, and interviews with families who have members with disabilities.

The systematic review highlighted innovative methods like workshops, role-playing, and co-created tools that not only boosted participation but also led to more tailored and effective crisis plans. However, it also revealed that many countries, including Sweden, still struggle with integrating people with disabilities into crisis planning. The co-creation workshop showcased the value of including people with intellectual disabilities in these conversations. Their unique perspectives provided crucial insights into how to make crisis information accessible and how to build more supportive systems. Interviews with families revealed their essential role in bridging the gap between individuals and the formal support systems, often creating their own solutions in the face of gaps in services.

The research identified five key areas for improving crisis preparedness: addressing systemic vulnerabilities, promoting collaboration, strengthening family involvement, reducing accessibility barriers, and tapping into local networks. By recognizing people with intellectual disabilities as active contributors, not just recipients of help, this dissertation calls for a shift toward more inclusive and resilient crisis planning that benefits everyone.

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