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Gender and Disability: An Exploration of Reflective Practice for Protection and Access Amid Complex Emergencies

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Gender and Disability: An Exploration of Reflective Practice for Protection and Access Amid Complex Emergencies is a qualitative research project exploring under what conditions and in what ways disabled persons' organizations (DPOs) effectively protect and provide access to women and girls with disabilities amid complex emergencies. The study upheld a participatory approach and rights-based framework, emphasizing that authentic inclusion requires centering disabled voices in research. Drawing on extant research, grey literature, and data collected from online practitioner questionnaires and semi-structured interviews, the study conducted a multi-phased reflexive thematic analysis. The research findings culminate in a composite narrative that brings to life the lived experiences of women with disabilities in humanitarian settings. The principal finding highlights the normative conditions enabling DPOs to effectively protect and provide access to women and girls with disabilities amid complex emergencies include an intersectional approach, rights-based framework, universal design, meaningful engagement, and capacity development.

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Chapter One: Introduction

Disability rights are human rights. Historically and systematically, society has erected barriers for persons with disabilities to fulfill their potential as human beings and access their human rights, often requiring the use of accommodations to do so. As long as the barriers remain, a person's accommodations cannot be separated from their human rights. In his address to the 13th Congress of Inclusion International, Australian Human Rights Commissioner and Disability Discrimination Commission, Dr. Sev Ozdowski, said:

> “Human rights are rights recognized as inherent in each and every one of us by virtue of our common humanity and innate dignity as human beings. They are the rights that must be respected if we are each to fulfill our potential as human beings. They are not luxuries – they are the basic and minimum necessities for living together in human society” (Australian Human Rights Commission, 2005).

If it can be agreed that human rights are not luxuries, it can also be agreed that accommodations are not luxuries either. Practitioners working with women and girls with disabilities in humanitarian settings face challenges in translating norms like rights-based and participatory approaches to implementation in the field. This is partially due to contextual constraints, limited resources, and difficult decisions, which are compounded by the lack of data discourse. The combination of obstacles results in knowledge gaps around implementation of accommodations, protections, accessible programming, and sustainable outcomes of transformative change.

Disability-inclusive research helps deepen our understanding of the factors of vulnerability and resilience amid complex emergencies, and without the inclusion of disabled voices and perspectives, we cannot effectively uphold the human rights of everyone. Currently, there is a lack of data about disabled persons, their lives, and their needs that would allow researchers to meet their obligations to disabled persons (NEAC, 2021). The exclusion of persons with disabilities may be explicit, attributable to poorly justified exclusion criteria, or implicit, attributable to inaccessible study documents, interventions, or research measures (Rios et al., 2016). As a result, persons with disabilities have been overlooked as a significant minority group by scholars, thus historically rendering their experiences less visible.

While there is growing momentum to mainstream disability and advance inclusive development, the scholarship surrounding disability and disaster remains in its infancy. Overlapping frameworks have strengthened the rights of persons with disabilities in complex emergencies, however, many of the policies and concepts in humanitarian action, disaster risk reduction, and disaster risk management address the issues at a very abstract level and do not translate into action on the ground (Spurway & Griffiths, 2016). The 2022 statement by the United Nations Committee on the Rights of Persons with Disabilities provides evidence of this gap, estimating that 2.7 million persons with disabilities in Ukraine were at risk of being abandoned in their homes or residential care due to the war[1]. Similarly, in a recent general discussion on persons with disabilities in

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[1] United Nations Human Rights Office of the High Commissioner. (2022, April 28). Ukraine: 2.7 million people with disabilities at risk, UN committee warns. [Press release]. https://www.ohchr.org/en/statements/2022/04/ukraine-27-million-people-disabilities-risk-un-committee-warns

situations of risk and humanitarian emergencies, the Committee noted that contemporary examples like this revealed the ableist assumptions entrenched in States' planning and response efforts had failed persons with disabilities. The effects of climate change, acts of aggression, and armed conflicts did not differentiate between people, but the responses to such issues could (OHCHR, 2023).

The United Nations Office for Disaster Risk Reduction (2017) defines vulnerability[2] as the characteristics determined by physical, social, economic, and environmental factors or processes which increase the susceptibility of an individual, a community, assets, or systems to the impacts of hazards. The *Handbook of Disaster Research* connects this definition to disability by presenting social vulnerability theory, which emphasizes that disaster vulnerability is socially constructed, and that disability arises from barriers and inequities constructed by society. The authors go on to argue that, as a result, individuals with disabilities subsequently share a larger burden of this vulnerability not only in disasters but in other social contexts. Altering conditions like poverty, unemployment, lower levels of education, medical care, and substandard housing will require broad systematic change (Rios et al., 2016; Stough & Kelman, 2018).

With the world's population aging and more people acquiring disabilities from various causes, understanding how to meet the needs of persons with disabilities during complex emergencies is critical, especially for women and girls who face compounding

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[2] It is essential to recognize that the term "vulnerable" used in this article does not imply helplessness among individuals with disabilities; instead, it denotes the compounding obstacles they face due to social disadvantage, poverty, and structural exclusion, as pointed out by Hemmingway and Priestly (2006).

inequalities of gender and disability. *Gender and Disability: An Exploration of Reflective Practice for Protection and Access Amid Complex Emergencies* is a research project that engaged specialists and practitioners advocating for and/or providing services to women and girls with disabilities in humanitarian settings to explore a central question: Under what conditions and in what ways, do disabled persons' organizations effectively protect and provide access to women and girls with disabilities amid complex emergencies?

1.1 Global Context of Gender and Disability Vulnerability

The World Health Organization (WHO)[3] reports that persons with disabilities make up 15% of the global population, representing the world's largest minority of one billion people. According to the World Bank, 80% of persons with disabilities reside in developing countries[4], and the United Nations Department on Economic and Social Affairs estimates 20% of the world's poorest people have some disability and are regarded as the most disadvantaged in their communities[5]. These statistics, paired with extensively documented gender inequities, make women and girls with disabilities especially vulnerable during complex emergencies. In such circumstances, persons with disabilities are two- to four -times more likely to be injured or die in disasters due to

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[3] World Health Organization. (n.d.). Disability and Health. https://www.who.int/news-room/fact-sheets/detail/disability-and-health

[4] World Bank. (2021, January 28). Challenges Facing People with Disabilities in Sub-Saharan Africa in 5 Charts. https://www.worldbank.org/en/topic/poverty/brief/challenges-facing-people-with-disabilities-in-sub-saharan-africa-in-5-charts

[5] United Nations. (n.d.). Factsheet on Persons with Disabilities. Retrieved from https://www.un.org/development/desa/disabilities/resources/factsheet-on-persons-with-disabilities.html

inadequate community-wide planning and access to emergency and disaster assistance (2020).

When persons with disabilities flee their homes, they are immediately exposed to disproportionate risks and often receive insufficient aid. The United Nations Human Rights Council (UNHRC) reports that while en route to the destination country, refugees with disabilities are more susceptible to violence, exploitation, discrimination, and abuse. These vulnerabilities persist at refugee camps where physical, societal, and attitudinal barriers limit access to critical information, health care, accommodations, and rehabilitation services. According to a report by Euro-Med Human Rights Monitor and the University of York, Curtis and Geagan (2016), a good number of young women with disabilities were not allowed to participate in services and activities for refugees because they had no male companion's permission. The report adds that persons with disabilities are less able to protect themselves from exploitation, violence, and abuse[6]. Additionally, disability-led organizations often face unequal access to traditional disaster relief channels and are left to mobilize resources and fill the gaps left by inadequate social safety nets. As of 2019, only 2% of the global human rights and international development funding goes to persons with disabilities (R. Thomas & Miller, 2022).

The 2020 report by the UN Secretary-General on Women, Peace, and Security[7] indicates that women and girls with disabilities account for more than half of all persons

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[6] Euro-Mediterranean Human Rights Monitor. (2020). Living with Disabilities in Times of War: The Situation of Persons with Disabilities in the Gaza Strip. https://euromedmonitor.org/uploads/reports/pwden.pdf

[7] Security General Report. (2020, June). Women, peace and security: Annual trends and analysis 2020. https://www.securitycouncilreport.org/atf/cf/{65BFCF9B-6D27-4E9C-8CD3-CF6E4FF96FF9}/s_2020_946.pdf

with disabilities and nearly one-fifth of all women and girls worldwide. There has been increasing acknowledgment that there are elements of the population requiring additional consideration due to the discrimination and marginalization they face in society, including 'the elderly, women and girls, minority groups and persons with disabilities – [who] can become the most vulnerable in a time of crisis' (Rohwerder, 2013; Niskala, 2007).

This is clear in the 2019 report[8] published by Amnesty International that highlights the extent to which women and girls with disabilities are at risk of all forms of violence, including sexual violence, exploitation, and abuse during emergencies, especially in emergency shelters and relief camps. More recently, reports coming out of Ukraine indicate thousands of children and adults with disabilities are trapped in institutions facing the risk of being abandoned or of serious negligence[9].

Despite overlapping legal frameworks and policies like the United Nations Convention on the Rights for Persons with Disabilities, the Sendai Framework for Disaster Risk Reduction[10], and the Charter on Inclusion of Persons with Disabilities, there has been slow progress in addressing an urgent need. As the world's population ages and more people acquire disabilities from diseases, natural disasters, and armed conflict, policymakers and practitioners must address how the needs of disabled people are met in

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[8] Amnesty International. (2019, December 3). *Yemen: Excluded: Living with disabilities in Yemen's armed conflict*. Amnesty International. https://www.amnesty.org/en/documents/mde31/1383/2019/en/

[9] International Disability Alliance. (2015, June). Through conflict in Ukraine: What happens to persons with disabilities. https://www.internationaldisabilityalliance.org/content/through-conflict-ukraine-what-happens-persons-disabilities

[10] United Nations Office for Disaster Risk Reduction. (2015). Sendai Framework for Disaster Risk Reduction 2015-2030. Retrieved from https://www.undrr.org/publication/sendai-framework-disaster-risk-reduction-2015-2030

the context of complex emergencies and beyond. Again, this is particularly critical for women and girls with disabilities, facing compounding inequalities of gender and disability nexus. Therefore, the intersectional experiences of women and girls with disabilities must be recognized and addressed to promote their full participation and ensure that their rights are respected.

Some of the issues with implementing disability law and policy can be attributed to the absence of universal and internationally recognized definitions, concepts, classifications, and measures of disability. For instance, some regions, cultures, and languages do not have a general term for disability. Ambiguity in language has allowed for flexible interpretations of the law and the ability for governments to scapegoat legal obligations. When definitions and classifications differ from one country to the next, it hinders a person's ability to cross borders with confidence that their needs will be met upon their arrival. Moreover, it creates barriers to coalition building and organizing.

1.2 Identifying Knowledge Gaps

To date, most research addressing disability and complex emergencies has focused on the disproportionate impact that complex emergencies have on persons with disabilities. This body of literature has been critical in developing arguments that shaped the frameworks and policies mentioned above, as well as guidance notes produced by organizations like the WHO, UNHCR, and World Bank. Lesser research, however, documents the experiences of persons with disabilities (Stough & Mayhorn, 2013). As highlighted in the *Handbook of Disaster Research*, the existing literature principally consists of statistical surveys (e.g., McGuire et al., 2007; Metz et al., 2002), responses collected on undifferentiated groups of persons with disabilities (Stough et al., 2010), or is authored by persons without disabilities (Stough & Kelman, 2015).

Persons with disabilities have so far received limited attention in development research given the absence of quality data on disability (Mitra, Posarac, & Vick, 2013). Inconsistent measures of disability and inaccurate data have been a source of frustration for advocates and policymakers since the inception of the CRPD. This is a problem when international donors and national governments have limited resources and are required to make decisions as to where funds will be allocated. Data gaps like the lack of available or timely data, lack of harmonized datasets and collection methods, along with the challenges in defining disability to compare cross-country datasets, need to be addressed to help provide a clearer global picture of human mobility and disability for policymaking and program implementation, as well as track related targets in the Sustainable Development Goals (IOM, n.d.). With minimal representation of persons with disabilities in decision-making roles and unreliable data, there is a direct impact on developing inclusive policies and programs. The lack of representation is compounding for persons with disabilities in the Global South, where countries have maintained limited political authority since the origin of the United Nations.

Disability studies in the Global South recognize that people with disabilities are one of the most marginalized and excluded groups in the world, facing discrimination and exclusion in every aspect of their lives, including education, employment, health, housing, social participation and political representation (Meekosha, 2011). Many countries in the Global South face disproportionate rates of disability due to multiple factors beyond their control. While some countries have taken reactionary measures to address issues such as malnutrition and unsanitary conditions that contribute to birth defects, other factors require international cooperation to address. These include natural disasters caused by climate change, unmet safety regulations resulting from exploitative colonial practices, and proxy wars initiated by countries in the Global North. In addition to living in impoverished conditions, disabled citizens in postcolonial countries face further struggles for survival in the face of abject poverty (Albrecht, 2006).

1.3 Research Objectives

The principal aim of this project was to provide a composite narrative that brought to life the unique intersection of gender and disability in humanitarian settings to be used alongside future studies, guidance notes, and policy recommendations. This method allows researchers to use data from several individual interviews to present complex, situated accounts from research participants in a holistic way that represents the overall findings of the research while preserving confidentiality. Composite narratives can form one part of the outputs of a study (Creese et al., 2021; Wertz et al., 2011) or be the main focus of the data (McElhinney & Kennedy, 2022; Biglino et al. 2017; Taber, 2013). One benefit of this approach is that it uses academic methods to build understanding in ways accessible to non-academics.

Qualitative research serves as a powerful tool to amplify the local voices of persons with disabilities. For instance, in the book Disability Histories, Ugandan landmine survivors describe their path from amputee oppression to acceptance and advocacy through peer counseling, community support, and encouragement (Burch & Rembis, 2014). Similarly, Human Rights Watch, Amnesty International, and various other human rights organizations have published reports of women and girls with disabilities living in chains[11], being treated worse than animals[12], and being exploited by sex smugglers[13]. Narratives such as these have the power to engage civil society and transform policy in human rights debates and discourse.

Nevertheless, there are substantial gaps in the literature on inclusive qualitative research, resulting in data invisibility, where the people and stories you don't get to hear or see don't exist (Watharow & Wayland, 2022). Research in the field of disability has typically been done on individuals with disabilities rather than with them, disempowering this already vulnerable population and taking away their voice (Coons & Watson, 2013). Qualitative research can be a valuable window through which to view the lived experiences of individuals with disabilities in ways that other methods of research do not capture. It can effectively elucidate the experiences of individuals with disabilities in all their complexities and help form policy solutions that address the intricacies of their reality (O'Day & Killeen, 2002). To that end, it is worth noting that the design, data

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[11] Human Rights Watch. (2020). Living in chains: Shackling of people with psychosocial disabilities worldwide. https://www.hrw.org/report/2020/10/06/living-chains/shackling-people-psychosocial-disabilities-worldwide

[12] Human Rights Watch. (2014). Treated worse than animals: Abuses against women and girls with psychosocial or intellectual disabilities in institutions in India. https://www.hrw.org/report/2014/12/03/treated-worse-animals/abuses-against-women-and-girls-psychosocial-or-intellectual

[13] Amnesty International. (2016, January 18). Female refugees face physical assault, exploitation and sexual harassment on their journey through Europe. Amnesty International. https://www.amnesty.org/en/latest/news/2016/01/female-refugees-face-physical-assault-exploitation-and-sexual-harassment-on-their-journey-through-europe/

collection, analysis, and presentation of this project were facilitated by a neurodivergent investigator.

Research in the field has been predominantly quantitative in nature, giving little portrayal of what the lived experiences of individuals with disabilities are really like (Coons & Watson, 2013; Bollard, 2003; Irvine, 2010; McDonald & Patka, 2012). While quantitative methods have advantages in simplifying complex situations into easily digestible numbers, this approach can at times dehumanize and distort the experiences of individuals with disabilities. Both quantitative and qualitative research have advantages and disadvantages, and neither is superior to the other. The choice of method should, instead, depend on the research questions, how the data will be used, and what is most appropriate for the targeted audience of research participants.

Quantitative data can certainly be a powerful tool for planning, implementing, monitoring, and evaluating policies and programs aimed at promoting the rights of people with disabilities. On the other hand, qualitative inquiry can provide insight into the nuanced lived experiences of individuals with disabilities and uncover unanticipated findings that would be missed by quantitative methods alone. While both methods play an important role in disability studies, this project found qualitative methods to be the most appropriate.

Although composite narratives are a relatively new method for conveying research findings, they offer an array of benefits that traditional ways of presenting research findings do not. Research findings are impactful when they are accepted by readers as rigorous and credible while also capturing the lived experience of the participants in a way that is relatable for readers from a range of backgrounds (Wertz et al., 2011).

Composite narratives allow for confidentiality, as the identities of individual participants can be protected while still allowing for the integration of respondent experiences into a holistic story that reflects various attributes from various participants. In this way, composite narratives provide a powerful tool for presenting the overall findings of the research while maintaining the richness and complexity of individual experiences (Hartmann et al., 2017).

1.4 About this Thesis

This qualitative study targeted practitioners and specialists who have expertise in working with women and girls in humanitarian settings, including those with physical, intellectual, sensory, and psychosocial impairments. To ensure a diverse pool of participants, the study used a combination of methods to identify potential participants, including reaching out to international networks of disabled-person organizations and using snowball sampling through agency staff and leaders in the disability community. Initial recruitment involved contacting disabled persons' organizations (DPOs) via email and distributing electronic informational fliers on social media platforms. The multi-pronged outreach strategy allowed for broad international distribution to participants who may otherwise not have had the opportunity to learn about the study. To promote accessibility, reasonable accommodations were provided for the online questionnaire, including unlimited time and the ability to access the questionnaire from personal devices.

The research project was designed with minimal risk by involving practitioners rather than beneficiaries, and participants were not asked to comment on their own organization[14]. Given that practitioners may be disabled themselves and may find some questions triggering, the informed consent emphasized that participants are free to stop at any time, may skip questions if they don't want to answer them, or may choose not to return the questionnaire. Data collected from the questionnaire was anonymous and stored on Qualtrics, an IT-approved data collection tool and database hosted by the University of Denver. Participants were only identified if they chose to be contacted by the principal investigator for a virtual interview.

Unlike most studies involving persons with disabilities, the end goal of this project was not to gather detailed demographic or sex- and age-disaggregated data on displaced persons with disabilities. Rather, the research was designed to better understand the complexity and human experiences of women and girls with disabilities amid complex emergencies and displacement.

A four-pronged approach was used to conduct the research: 1) a review of grey literature including existing UN, NGO, international, and national guidance on disability, with particular reference to gender, displacement, and disability; 2) a review of extant research involving scholarly articles that focused on conditions for women and girls with disabilities amid complex emergencies and/or displacement, primarily in developing countries; 3) online questionnaire of practitioners and specialists advocating for and/or providing services to women and girls in humanitarian settings; 4) virtual semi-structured

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[14] (#2026237-1)

interviews with practitioners and specialists advocating for and/or providing services to women and girls in humanitarian settings.

Unfortunately, like most studies, standard approaches to data collection can present challenges to persons with disabilities participating in research processes. Limitations to this study included funding, time constraints, barriers to interviewing vulnerable groups, and difficulty interacting with traditional research instruments, such as questionnaires. That said, this study aimed to uphold a participatory approach and rights-based framework to research by engaging DPOs to share the experiences of women and girls they serve and consulting with disabled advocates in the process of developing the online questionnaire and interview questions.

Questionnaire data was collected directly from online questionnaires via Qualtrics, while the recordings from virtual semi-structured interviews were downloaded to a password-protected device, transcribed, and erased. All data was processed in a confidential manner and merged into a single database, from which qualitative thematic analysis was performed. Following the analysis, the key findings were used to form a composite narrative and develop a model of normative conditions that enable DPOs to effectively support women and girls with disabilities in complex emergencies. While the composite narrative emphasizes common experiences that women and girls with disabilities encounter through pre-existing barriers, flight, displacement, and return, the model of normative conditions argues that DPOs are most effective in protecting and providing access to women and girls with disabilities amid complex emergencies when: (1) specific attention is given to the intersectionality of gender and disability, (2) there is meaningful engagement with women with disabilities, (3) a rights-based model of disability is widely supported, (4) universal design is implemented, and (5) donors invest in grassroots capacity development.

Chapter Two: The Normative and Policy Context

Despite limited knowledge about the lived experiences of women and girls with disabilities, progress has been made over recent decades to enshrine the rights of persons with disabilities. This chapter will highlight the global, regional, national, and community frameworks operating at the intersection of gender, disability, and humanitarian contexts, and underline the conceptual theories that bind this paper together and present general themes from previous scholars.

Aspirations to recognize the rights of persons with disabilities within United Nations initiatives began in the 1960s via the context of development. Prior to 1970, the United Nations approach to disability came from a social welfare perspective, with little attention paid to obstacles created by social institutions and society in general (Brown, 2014). Throughout the 1970s, the United Nations embraced the equalization of human rights and opportunities for people with disabilities by enacting the 1971 Declaration of the Rights of the Mentally Retarded Persons and the 1975 Declaration of the Rights of Disabled Persons. Following the International Year of the Disabled Person in 1981, the United Nations formulated the World Program of Action Concerning Disabled Persons in 1982. Drawing on relevant international instruments such as the UN Charter, Universal Declaration on Human Rights, International Convention on Civil and Political Rights, and the International Convention on Economic, Social, and Cultural Rights, the World Program of Action was the most comprehensive global strategy to date.

The disability rights movement gained momentum when the United Nations declared 1983 - 1992 as the Decade of Disabled Persons, resulting in the 1993 adoption of Standard Rules on the Equalization of Opportunities for Persons with Disabilities. This set of 22 rules became the guiding principles for the United Nations and its member states when developing policy, ensuring that all aspects of life were being considered for persons with disabilities. As societal barriers became increasingly recognized in the 1990s, international frameworks began to call on human rights treaty monitoring bodies to monitor the complaints of nation-states as it relates to the human rights of persons with disabilities. In 2001, Mexico spearheaded calls on the international community to establish an Ad Hoc Committee to promote the rights and dignity of persons with disabilities. Five years later, in 2006, the UN's General Assembly adopted the momentous treaty known as the Convention on the Rights for Persons with Disabilities (CRPD).

The most relevant international and normative frameworks related to disability and complex emergencies include, but are not limited to the United Nations Convention on the Rights of Persons with Disabilities (CRPD), the Charter for Inclusion of Persons with Disabilities in Humanitarian Action, the United Nations Disability Inclusion Strategy (UNDIS) and its subsequent development of the Inter-Agency Standing Committee Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action, the Sendai Framework for Disaster Risk Reduction (SFDRR), and lastly, the principle of Leave No One Behind in the 2030 Agenda. That said, we would be remiss not to touch on overlapping frameworks that apply at the intersection of women and girls with disabilities in humanitarian settings like the Convention for the Elimination of All Forms of Discrimination Against Women (CEDAW), the 1951 Refugee Convention and the

Convention on the Rights of the Child (CRC). Together, these frameworks provide a clear legal and policy framework underpinning the commitment of the humanitarian community to include persons with disabilities and older people.

Unlike international frameworks, policies, and legislation at the regional, national, and community levels vary depending on their ratification status of treaties, level of State fragility, willingness to collaborate with agencies and civil society, and the cultural milieu. Since the establishment of the CRPD, some regional systems like the Association of Southeast Asian Nations (ASEAN), have made efforts to implement protocols that promote equality for individuals with disabilities. That said, comparative studies conducted by the United Nations on disability legislation reveal that only 45 countries have taken action to ratify anti-discrimination and other disability-specific laws.

The following section outlines the international, regional, national, and community-level frameworks that guide policy surrounding women and girls with disabilities in humanitarian settings.

2.1 Normative Frameworks

2.1.1 International Frameworks

United Nations Convention on the Rights of Persons with Disabilities (CRPD)

Although seven landmark human rights treaties protect the rights of women, children, migrant workers, and others, the CRPD is the first international treaty that identifies the legal obligations of States to promote and protect the rights of persons with disabilities. According to the United Nations, the purpose of the Convention is to promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities and promote respect for their inherent dignity (2007). The Convention does not create new rights for disabled persons; instead ensures that existing human rights are promoted for everyone, regardless of disability. Moreover, the Convention firmly upholds the social model of disability, contending that it is the society that makes barriers; therefore, society as a whole is responsible for removing them.

The CRPD currently has 160 signatories to the Convention, 92 signatories to the Optional Protocol, 164 ratifications/ accessions to the Convention, and 89 ratifications/accessions to the Optional Protocol. Countries that ratify the CRPD agree to be legally bound to treat persons with disabilities as subjects of the law with clearly defined rights as any other person. The Optional Protocol allows individuals and groups from countries that have ratified the Protocol to petition the Committee once all national recourse procedures have been exhausted.

The CRPD is the first legally binding international treaty that provides a comprehensive portfolio of disability rights and has the potential to create a paradigm shift in the manner in which disability policy and practice is formulated and implemented (O'Sullivan, 2012). The general principles emphasized in the Covenant include accessibility, inclusion, equality, non-discrimination, and independent living. Accessibility refers not only to physical spaces like buildings, transportation, and workplace but access to information, documents, and communication as well. The inclusion of persons with disabilities is a valued principle as it allows needs and concerns to become more transparent and more visible to non-disabled decision-makers. The CRPD goes beyond the general understanding of non-discrimination to stress that 'reasonable accommodation' must be made for persons with disabilities by providing necessary and appropriate modifications and adjustments where needed. States who are Party to the Convention must designate a focal point in the government and create a national mechanism to promote the implementation of the Convention.

Although there are countries that have not yet ratified the CRPD, it remains a monumental accomplishment for the global disability rights movement. Advocates, policymakers, and citizens alike, at last, have a foundation to hold governments accountable. Embedded within the CRPD are articles that offer guidance specific to women and girls with disabilities amid complex emergencies.

- *Article 6: Women with Disabilities* specifically protects the rights of women and girls with disabilities and recognizes that they encounter multiple layers of discrimination. When interpreted in conjunction with CEDAW Article 2, States are obligated to protect women from all forms of discrimination arising from the intersection of gender and disability, including during times of crisis.
- *Article 7: Children with Disabilities* highlights that children with disabilities should enjoy all human rights and fundamental freedoms on an equal basis with other children and that any action taken in their best interests should consider their unique needs and evolving capacities. This article is essential for providing adequate and appropriate services like healthcare and education in humanitarian settings.
- *Article 9: Accessibility* specifies that people with disability have a right to equally access the physical environment, transportation, and communication

technologies and systems. In a disaster context, this right includes equal access to warning systems, evacuation plans, or emergency shelters.

- *Article 11: Situations of Risk and Humanitarian Emergencies* calls on State Parties to 'take all necessary measures to ensure the protection and safety of persons with disabilities in situations of risk, including situations of armed conflict, humanitarian emergencies, and the occurrence of natural disasters.' When combined with the rest of the document, Article 11 is a 'powerful tool to ensure that people with disabilities are included in all aspects of humanitarian response and displacement, from recovery to rebuilding and resettlement' (Rohwerder, 2013; Phillips, Estey, and Ennis, 2010).
- *Article 18: Liberty of Movement and Nationality* calls upon State Parties to recognize the rights of persons with disabilities to liberty of movement and to freedom to choose their residence and nationality on an equal basis with others. This can be applied to refugees, migrants, and asylum seekers with disabilities by preventing arbitrary detention, restricting movement based on disability status, limiting access to identification documents, and other discriminatory practices.
- *Article 19: Living Independently and Being Included in the Community* highlights the right of persons with disabilities to live in their communities with the appropriate support. This can reasonably be applied to accessing temporary shelters and community activities established during a disaster or emergency.

- *Article 21: Freedom of Expression and Opinion and Access to Information* guarantees people with disabilities the right to seek, receive, and impart information and ideas on an equal basis with others through all forms of communication of their choice, including during emergencies and disasters. Governments must ensure that public communications and services are provided in accessible formats without cost. This includes providing information in various formats, such as sign language and easy-to-read text, and ensuring equal access to digital technologies and online platforms.
- *Article 29: Participation in Political and Public Life* requires that persons with disabilities must be included in planning, policy development, and implementation in any matters that affect their lives. This includes disaster risk reduction and management and can be achieved by consulting with Organizations of Persons with Disabilities (OPDs), conducting accessibility audits, and providing training to emergency responders.
- *Article 30: Right to Participate in Cultural Life* recognizes the right of persons with disabilities to participate in cultural activities, recreation, leisure, and sport. This becomes particularly significant in humanitarian settings where persons with disabilities are often isolated and would benefit from the community building and social cohesion associated with such events.

Charter on Inclusion of Persons with Disabilities in Humanitarian Action

Prior to the 2016 World Humanitarian Summit, over 70 stakeholders from States, UN agencies, the international civil society community, and global, regional, and national organizations of persons with disabilities gathered to develop The Charter on Inclusion of Persons with Disabilities in Humanitarian Action[15]. The Charter is a set of guidelines that draw on the principles of the CRPD and Leave No One Behind to advance inclusive humanitarian action for persons with disabilities. The Charter endorses lifting barriers, fostering participation, and developing inclusive policies and responses, and commits to non-discrimination, participation, and cooperation. These guidelines have been designed to provide practical information for humanitarian actors and other relevant stakeholders and place persons with disabilities, and their human rights, at the center of humanitarian action.

The Sendai Framework for Disaster Risk Reduction (2015-2030)

The Sendai Framework for Disaster Risk Reduction 2015-2030 (SFDRR)[10] builds on elements of the Hyogo Framework for Action (HFA) and was the first major agreement of the post-2015 development agenda to specifically mention disability and provides State Parties with concrete actions to protect development gains from the risk of disaster. The Sendai Framework has been hailed as the most inclusive of its kind and works hand in hand with the other 2030 Agenda agreements, including the Paris Agreement on Climate Change, the Addis Ababa Action Agenda on Financing for Development, the New Urban Agenda, and ultimately the Sustainable Development Goals. According to Stough & Kang (2015), the infusion of disability-related terms and concepts such as accessibility, inclusion, and universal design throughout the SFDRR document was

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[15] Humanitarian Disability Charter. (n.d.). About. https://humanitariandisabilitycharter.org/

significant and despite having roots in disability studies, refer to the needs of all in disaster, not only to people with disabilities. The framework emphasizes the importance of including people with disabilities in all aspects of humanitarian response, from disaster risk reduction to relief and recovery efforts. While the framework identifies the State as having a primary role in reducing disaster risk, it also recognizes that responsibility should be shared with local government, the private sector, and other stakeholders.

Written alongside the Sendai Framework is the Dhaka Declaration[16], a practical guideline for States to implement and report on Sendai Framework. The Dhaka Declaration is particularly important because it sets out specific measures to enable the meaningful engagement and input of people with disabilities and their organizations in the design, execution, oversight, and evaluation of programs. The declaration further urges governments, regional bodies, the private sector, and other stakeholders to: ensure a people-centered approach, strengthen governance, partnership, and cooperation; integrate sex, age, and disability disaggregated data; promote empowerment and protection; remove barriers to reduce the impact of disasters on persons with disabilities; and take action at local, national, and global levels.

United Nations Disability Inclusion Strategy (UNDIS)

In June 2019, the UN Secretary-General launched the United Nations Disability Inclusion Strategy (UNDIS) to ensure disability-inclusive protocols and practices

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[16] Dhaka Declaration. (2018). Dhaka Declaration 2018: Towards disability-inclusive disaster risk reduction in Asia and the Pacific. Retrieved from http://dkconf18.modmr.gov.bd/wp-content/uploads/2018/05/Dhaka-Declaration-2018.pdf

throughout the United Nations. The UNDIS[17] is a comprehensive framework that serves as a foundation for achieving sustainable progress in disability inclusion across all aspects of the UN's work, from headquarters to country level. This marks the first time that the UN has a system-wide framework to evaluate and enhance disability inclusion across its programs and internal operations. The strategy is being implemented by all UN entities involved in humanitarian efforts, peacekeeping, and political missions, as well as 130 country teams.

One of the key contributions of the UNDIS to the humanitarian sector is the Inter-Agency Standing Committee (IASC) Guidelines on the Inclusion of Persons with Disabilities. According to the IASC, these are the first humanitarian guidelines to move beyond traditional stakeholders to be developed with and by persons with disabilities and their representative organizations in association with traditional humanitarian stakeholders. Based on the outcomes of a comprehensive global and regional multi-stakeholder consultation process, they are designed to promote the implementation of quality humanitarian programs in all contexts and across all regions and to establish and increase both the inclusion of persons with disabilities and their meaningful participation in all decisions that concern them (Inter-Agency Standing Committee, 2019).

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[17] United Nations Department of Economic and Social Affairs, Division for Inclusive Social Development (2019). United Nations Disability Inclusion Strategy. Retrieved from https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/03/UNDIS_20-March-2019_for-HLCM.P.pdf

Leave No One Behind - Agenda 2030 for Sustainable Development Goals

The 2030 Agenda for Sustainable Development Goals (SDGs) aims to end poverty, protect the planet, and ensure that all people enjoy peace and prosperity by 2030 and incorporates both disability and disaster risk reduction. In its 2017 report, the Economic Cooperation Organization notes that the 2030 Agenda regards disaster risk reduction as a core aspect of development to be attained, among others, through the promotion of regional solidarity and leadership through regional commitments and partnerships (Economic Cooperation Organization, 2017). By adopting the 2030 Agenda, Member States are committed to beginning with those furthest behind in their implementation of the SDGs. This includes women and girls with disabilities, situated at the intersection of several SDGs including Goal 10: Reduced Inequalities and Goal 5: Gender Equality, and aligns with the 2030 Agenda's Universal Values, such as the Human Rights-Based Approach, Leave No One Behind, and Gender Equality and Women's Empowerment.

Convention for the Elimination of All Forms of Discrimination Against Women (CEDAW)

The Convention on the Elimination of All Forms of Discrimination Against Women (CEDAW) is an international legal instrument that requires countries to eliminate discrimination against women and girls in all areas and promotes women's and girls' equal rights. Although CEDAW does not explicitly contain text addressing women with disabilities, the CEDAW Committee's General Recommendation 18[18] highlights the need to recognize and address the intersectional experiences of women and girls with disabilities. This recommendation calls on State Parties to take concrete steps to promote their inclusion and advance gender equality for all women. Furthermore, the Committee's recent General Recommendation No 39[19] on the rights of Indigenous Women and Girls was recognized for making 30 references to disability and to indigenous women and girls with disability, thereby demonstrating growing awareness of the intersection of disability in gender mainstreaming.

The 1951 Refugee Convention

According to UNHCR, the core principle of the 1951 Refugee Convention is non-refoulment, which asserts that a refugee should not be returned to a country where they face serious threats to their life or freedom[20]. Despite being a rule of customary international law, disability is often overlooked in the context of non-refoulment, leading to a lack of adequate protection for disabled refugees and asylum seekers. While the 1951 Refugee Convention does not explicitly address the protection of persons with disabilities, similar to CEDAW, the UNHCR has recognized the importance of

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[18] United Nations. (n.d.). Concluding comments/recommendations of the Committee on the Elimination of Discrimination against Women. WomenWatch. https://www.un.org/womenwatch/daw/cedaw/recommendations/recomm.htm

[19] International Disability Alliance. (2021, June 30). CEDAW Committee adopts General Recommendation No. 39 on the rights of indigenous women and girls. https://www.internationaldisabilityalliance.org/blog/cedaw-committee-adopts-general-recommendation-no-39-rights-indigenous-women-and-girls-30

[20] UNHCR. (1951). 1951 Refugee Convention. https://www.unhcr.org/us/about-unhcr/who-we-are/1951-refugee-convention

addressing the needs of refugees with disabilities. In its conclusion, No. 110 (LXI) of 2010, the UNHCR called upon States and UN agencies to prevent discrimination against refugees with disabilities and to provide them with appropriate and sustainable support to address all their needs (United Nations, n.d.).

Convention on the Rights of the Child (CRC)

The CRC is the first binding instrument in international law to deal comprehensively with the human rights of children and is notable for the inclusion of an article specifically concerned with the rights of children with disabilities (UNICEF, 2007).

- *Article 2: Protect from Discrimination* recognizes that building segregated or separate facilities for education, health care, recreation, and all other aspects of human life on the basis of disability can create and consolidate exclusion, thereby reinforcing stigma and the perception that children with disabilities are a burden.
- *Article 23: Children with Disabilities* emphasizes that every child who is disabled has the right to special education, training, and care to enable them to live the fullest possible life by ensuring dignity, promoting self-reliance, and facilitating the child's active participation in the community, including in humanitarian contexts.
- *Article 38: Children in Armed Conflict* outlines a framework for safeguarding children in armed conflict, regardless if they are civilians or serving in state or nonstate armed groups. Conflicts pose a heightened risk of disabling injuries for children, and those with disabilities are particularly vulnerable. Article 38

> was seen by persons with disabilities as directly relevant to their own aspirations and proved to be the template from which discussions on the CRPD would begin (Begg, 2022).

2.1.2 Regional Frameworks

Regional frameworks play a crucial role in protecting women and girls with disabilities during complex emergencies, as they facilitate a coordinated and comprehensive response that transcends national boundaries. The international community recognized the importance of addressing disability in disaster risk reduction through a regional document developed by Asia and the Pacific in 2012, known as the Yogyakarta Declaration. This declaration emerged from the 5th Asian Ministerial Conference on Disaster Risk Reduction (AMCDRR), which was conducted as part of the regional Hyogo Framework for Action 2005-2015 consultations. The Yogyakarta Declaration specifically highlights the needs of persons with disabilities by urging States to prioritize cross-cutting issues, emphasize social protection in pre-disaster mechanisms, engage multiple stakeholders in planning and decision-making, and ensure the active participation of vulnerable communities in risk reduction efforts.

During the era of the HFA and the Yogyakarta Declaration, regional platforms within the United Nations Office for Disaster Risk Reduction (UNDRR) evolved. As defined by the UNDRR, regional platforms are multi-stakeholder forums that reflect the commitment of governments to improve coordination and implementation of disaster risk reduction activities while linking to international and national efforts[21]. Regional platforms provide an opportunity for multiple stakeholders to gather and discuss best practices, assess risk, monitor, and evaluate plans and, ultimately, collaborate and coordinate efforts to implement an effective regional response.

2.1.3 National Frameworks

Much like the regional platforms, the UNDRR has established a system of National Focal Points, National Platforms, and Local Platforms. At the national level, the National Platform serves as the central hub for all stakeholder engagement and promotes an all-of-society approach to disaster risk reduction. This platform is also equipped with effective mechanisms for dialogue with Local Platforms to foster local action. That said, the responsibility of States and national governments to mitigate disaster risk and respond to persons with disabilities amid complex emergencies ultimately rests on the National Disaster Response policy in place and the international agreements each State has ratified. According to a policy tracker jointly developed by UNWOMEN and UNDRR, only 81 out of 193 Member States have policies related to persons with disabilities (UNDRR, n.d.).

Despite being a voluntary and non-binding agreement, the Sendai Framework underscores the role of States and governments in reducing disaster risk and emphasizes the need for shared responsibility among all other stakeholders. Therefore, it is essential

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[21] United Nations Office for Disaster Risk Reduction (UNDRR). (n.d.). Implementing the Sendai Framework: Regional Platforms. Retrieved April 19, 2023, from https://www.undrr.org/implementing-sendai-framework/regional-platforms#tabs-23965-1.

that States collaborate with others to ensure that rights and services that are available at normal times remain accessible during emergencies. A recent report by UN Women (2023) highlights the Federated States of Micronesia as an example of a country that has successfully implemented inclusive practices for high-risk groups.

Addressing disaster vulnerabilities in any real way means that governments must take a leading role in meeting their obligations under international law to systematically address pre-existing barriers, such as inequality, discrimination, social attitudes, and cultural norms. This kind of transformation, however, cannot be made using current resilience models that simply advocate for more economic growth, increased efficiency, and neo-liberal restructuring as the universal solution to deeply ingrained societal vulnerabilities (Spurway & Griffiths, 2016). Instead, it requires focusing on barriers means working on structural changes, that is, collective changes on all levels, from the individual to the community sphere, to the design and implementation of public policies for inclusion (UN Women, 2021). The Committee on the Rights of Persons with Disabilities recently held a general discussion on persons with disabilities in situations of risk and humanitarian emergencies, where several individuals and organizations shared testimonies of the neglect and mistreatment of persons with disabilities at the hands of State Parties (OHCHR, 2023).

2.1.4 Community Frameworks

Historically, disaster management practice predominantly employed a top-down strategy, with little attention to local leadership and ownership. The 2016 World Humanitarian Summit, however, set a new precedent by calling for a new way of delivering aid that prioritizes local involvement. The commitment prompted international-aid organizations to find ways to adapt the traditional humanitarian-aid approach by working towards locally led interventions that increase effectiveness and accountability in a disaster context. Today, national disaster response initiatives are urged to work collaboratively with the leadership of stakeholders at the local level, creating space for local OPDs to be part of a humanitarian response. This shift is important to note, as previous recommendations for persons with disabilities were typically aimed at caretakers rather than towards the individuals themselves, further contributing to the perception of people with disabilities as passive recipients of care rather than potential participants in disaster risk reduction (Wisner et al., 2011).

OPDs have come to play an essential role in advocating for the rights and protections of persons with disabilities in humanitarian settings. UNICEF's Disability Inclusive Humanitarian Toolkit defines OPDs as any organizations or associations that are led, directed, and governed by persons with disabilities that are entrenched, committed to, and fully respect the principles and rights recognized in the CRPD. The toolkit goes on to describe how partnerships and collaboration with OPDs improve the effectiveness and accountability of humanitarian operations, as OPDs are best qualified to provide information on the challenges they experience and to provide informed input to strengthen the quality of inclusive practice. Moreover, meaningful engagement with OPDs aligns with commitments towards localization, accountability, and inclusion.

International humanitarian-aid agencies need to recognize that although complex emergencies transcend borders and impact large groups of people, they are local events that profoundly impact local communities. Persons with disabilities rely heavily on household preparedness, community and social networks, and organizational responses like schools, service providers, and trained emergency personnel. Therefore, building capacity within individuals, communities, and organizations through a community-wide disability-inclusive approach is essential to overcoming societal and attitudinal barriers before disaster strikes. Coordinated planning and channeling of resources to meet local needs will strengthen community-level emergency planners' capacity to minimize the impact of disasters on the entire community (Kruger et al., 2018).

Despite formalized international commitments and recommendations to improve community-based disaster risk reduction (CBDRR), the practical implementation of disability-inclusive disaster risk reduction is negligible. Statistics provided by UNDRR demonstrate the magnitude of this, with 71% of persons with disabilities lacking an individual preparedness plan, 85% not participating in community disaster management and risk reduction processes, and only 20% capable of immediate evacuation in the event of a sudden disaster, with 13% having no one to assist them (UNDRR, n.d.). These statistics highlight that there are still significant gaps between policy, guidance, and implementation from the formalized international level to the practical localized level. Without direct and consistent engagement with OPDs and disability-inclusive disaster risk reduction, the result is inconsistent and detrimental.

2.2 Theories of Change

2.2.1 Models of Disability

According to Meekosha (2011), “Disability is not simply an individual attribute, but is shaped by societal norms and expectations, cultural and social beliefs and practices, and political, economic and environmental factors. Understanding the ways in which disability is constructed is therefore a critical step towards developing effective strategies for addressing disability issues.” The conceptualization of disability has been shaped by four major models: Charity, Medical, Social, and Rights-based Models. As with any field of study or academic discipline, these models have evolved to better represent the voices of persons with disabilities in both academic and political discourse. For over forty years, these theoretical frameworks have played a key role in advocating for disability policy, promoting disability studies, and providing a framework for how society views and responds to persons with disabilities.

Today, it is widely recognized that the philosophical basis of international instruments like the CRPD promotes a social and rights-based approach and rejects the medical model of disability. When disability rights are reflected in the overall statement of guiding principles- whether law, policy reform, or development- it has proven to benefit all.

- ***Charity Model:*** Historically, persons with disabilities have been viewed as objects of pity or victims of their impairment. The charity model views the individual as having a problem that requires 'caring for,' thus viewing persons with disabilities as passive recipients of charity and beneficiaries of services.

The charity model is still widely adopted today by States, humanitarian agencies, NGOs, and the media, thus exacerbating discriminatory prejudices towards persons with disabilities and perpetuating the idea that persons with disabilities need special and separate treatment.

- ***Medical Model***: Like the charity model, the medical model focuses on the individual, believing that the problem and solution rest solely with the person with a disability. The medical model views persons with disabilities as needing to be 'cured' through medical interventions in order to be 'normal' before accessing equal opportunities to participate in society. Such assumptions, which have close ties to colonial belief systems, reinforce discriminatory attitudes and stereotypes, thus enabling systems of inequality to persist.
- ***Social Model***: The social model incorporates a multi-dimensional way of thinking that aims to remove barriers hindering the full participation of persons with disabilities in society. It does this by focusing on the interaction between an individual, the environment, and the context of the moment. The social model asserts that disability is a natural part of the human condition and experienced when social, institutional, economic, political, or other systems do not accommodate an individual's differences. Under this model, society needs to change, not the individual.
- ***Rights-Based Model***: The rights-based model builds upon the social model of disability and focuses on the inherent dignity of every person in society with the right to equal opportunities and participation. This approach treats barriers

> in society as discriminatory and seeks to transform unjust systems and practices by empowering persons with disabilities to claim their rights and have autonomy over their lives. It is the social-model understanding of disability and the human rights-based approach that are enshrined in the CRPD.

2.2.2 Twin Track Approach

An article in the International Journal of Environmental Research and Public Health notes that in recent years, global attention to disability inclusion in humanitarian and development contexts has increased, in large part because of the integration of disability inclusion within the Sustainable Development Goals. As a result, UN agencies and programs are increasingly seeking to understand and increase the extent to which persons with disabilities are accounted for and included in their efforts to provide life-saving assistance (O'Reilly et al., 2021). A twin-track approach is a promising approach that humanitarian agencies have adopted as the most effective for disability-inclusive DRR.

The UNDIS defines the twin-track approach as a) integrating disability-sensitive measures into the design, implementation, monitoring, and evaluation of all policies and programs and b) providing disability-specific initiatives to support the empowerment of persons with disabilities. While there is a balance between mainstreaming strategies and targeted support tailored to address the needs of specific communities, the overall goal should always be to integrate and include persons with disabilities in all aspects of society and development (UNDIS).

CBM's Humanitarian Hands-On Tool[22] expands on this definition, explaining that applying a twin-track approach means ensuring women, men, boys, and girls with all types of impairments, being hearing or visual impairment, physical impairments, or cognitive impairment, as well as intellectual or learning disabilities have full access to relief operations and protection by removing barriers and facilitating access. The tool goes on to describe how at the same time, humanitarian actors must provide specific solutions and individualized support for adults and children, particularly those who may have higher support needs, always with the principle of informed consent, choice, and autonomy of the person. Here, collaboration with and referral to disabled persons' organizations and disability-specific organizations is essential (CBM, n.d.).

The twin-track approach to disability-inclusive policy promotes power-sharing, countering top-down strategies that international humanitarian agencies previously employed. When implemented, this approach includes persons with disabilities as contributors to disaster risk reduction, not merely recipients (Stough & Kelman, 2015). To that end, the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action make clear that OPDs play an essential role in the effectiveness of disability-inclusive disaster risk response and are key stakeholders in the full spectrum of emergency response and relief efforts.

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[22] CBM. (n.d.). Home-based online therapy for children with disability during COVID-19. Retrieved Month Day, Year, from https://hhot.cbm.org/en/

2.2.3 Participatory Approach

The slogan for the disability rights movement, 'Nothing about us without us,' initially served as a rallying cry for basic civil rights and eventually became a legal obligation for democratic societies to include persons with disabilities as decision-makers and right-bearers. There has been growing momentum toward the inclusion of persons with disabilities through new global commitments and efforts to promote inclusive development in recent years. The UNHCR, for example, describes supporting the involvement of persons with disabilities as participants in policy and program formulation, implementation, and monitoring processes to identify protection concerns and appropriate solutions. The Refugee Agency goes on to promote consultation and participation through all phases of crises and protracted situations is essential and underscoring that persons with disabilities should be able to apply their skills and capacities to benefit themselves, their families, and their communities, including representing their communities in leadership positions (UNHCR, 2011). Identifying OPDs as key stakeholders has deepened understanding of the views and diversity of persons with disabilities while orienting efforts in compliance with human rights obligations.

Despite progress in policy, the COVID-19 pandemic illuminated systemic ableism, stigmatization, and discrimination, causing roadblocks from policy to practice. Thus, a new refrain from disability leaders and activists has emerged, 'Nothing without us.' This slight change in semantics sends a clear message that legal obligations and policy recommendations that specify persons with disabilities are insufficient if other systems and mechanisms continue to exclude them. 'Nothing without us' calls for the full and active participation of persons with disabilities in all levels of leadership and steps of programming - from planning to implementation to evaluation.

It is worth noting that during the height of the pandemic, the number of persons with disabilities accessing certain technologies grew, revealing the various opportunities that exist to leverage technology in creating environments more accessible. With this in mind, UNDESA[23] has noted the post-2015 development agenda can be used to promote the impact and benefits of assistive technology, accessible information and communications technology, technological adaptations, and other policy and programmatic measures to improve the well-being and inclusion of persons with disabilities in society and development. By harnessing these technological advancements, the vision of 'Nothing without us' is within reach.

Furthermore, when addressing complex emergencies, a fault of outside humanitarian actors is overlooking the capacity of local communities and institutions to offer context and guidance for effectively providing assistance. It is essential to recognize that although complex emergencies are often large scale, for those impacted, the crisis is local, and has affected local communities. Such communities should never be treated as homogenous groups, nor should persons with disabilities in those communities. By partnering with OPDs, humanitarian actors live out the vision of 'Nothing without us' and gain invaluable perspective through the lens of accessibility and inclusion, which benefits everyone in the community.

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[23] United Nations Department of Economic and Social Affairs. (2018, June 18). Promise of technology for persons with disabilities. Retrieved from https://www.un.org/development/desa/en/news/social/promise-of-technology-for-persons-with-disabilities.html

2.2.4 Universal Design

According to the CRPD, universal design refers to the "design of products, environments, programs, and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialized design." As such, universal design provides a useful framework for considering the design of emergency management systems and may provide a basis for identifying and removing usability and accessibility barriers in emergency situations (Paupini & Giannoumis, 2019). In many ways, the theory underpinning universal design runs parallel to that of human-centered design (HCD). According to UNICEF, human-centered design is a problem-solving process that begins with understanding human factors and context surrounding a challenge. It requires working directly with users—the people who use the service or deliver the solution – to develop new ideas that are viable and appropriate in their context.

Universal design is not a specialized field of design practice, but an approach to design, an attitude, a mindset conducive to the idea that designed objects, systems, environments, and services should be equally accessible and simultaneously experienced by the largest number of people possible (Mitrasinovic, 2008). In this way, universal design differs from HCD. Although both approaches place the experience of users at the center of their process and approach, HCD aims to create specific solutions for specific problems.

It is a common misconception that disability-inclusive policies only benefit persons with permanent disabilities. While some persons are born with a disability, most acquire disabilities through life events like a medical diagnosis, injury, or traumatic event. Situations of risk certainly heighten barriers both for persons with physical, sensory, cognitive, or psychosocial disabilities, but persons with temporary or situational disabilities have potential to be equally as impacted. It cannot be overstated; disability is a natural part of the human condition that everyone will experience. Failing to consider the needs and viewpoints of all stakeholders, particularly those with disabilities, has resulted in missed opportunities to create infrastructure, environments and programs that are both accessible and resilient to disasters and crises.

2.2.5 Intersectionality: Gender and Disability

The term 'intersectionality' was first coined by American critical race scholar Kimberlé W. Crenshaw in 1989 and referred to the double discrimination of racism and sexism faced by Black women. In a 2017 interview at Columbia Law School[24], Crenshaw defines intersectionality as, “a lens through which you can see where power comes and collides, where it interlocks and intersects. It’s not simply that there’s a race problem here, a gender problem here, and a class or LBGTQ problem there. Many times, that framework erases what happens to people who are subject to all of these things”. The principles of intersectionality are essential to understanding the experiences of women and girls with disabilities amid complex emergencies.

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[24] Gorin, R. (2012, March 28). Kimberlé Crenshaw on Intersectionality: More than Two Decades Later. Columbia Law School. https://www.law.columbia.edu/news/archive/kimberle-crenshaw-intersectionality-more-two-decades-later

There is a distinct gap in research on the intersection between and among age, gender, and disability in humanitarian settings. Disability is not monolithic and cannot be limited to a particular age, gender, ethnicity, faith tradition, sexual identity, or socio-economic status; rather, it crosscuts all demographics and adds depth, breadth, complexity, and beauty to intersecting identities. Disability inclusion cannot be achieved without challenging the societal and institutional discrimination, marginalization and exploitation experienced by people with disabilities in disasters and at other times (Twigg et al., n.d.). The most effective and sustainable approach to responding to the needs of persons with disabilities is to design programs, structures, and policies with intersectionality at the core.

The CRPD encompasses specific substantive rights, including civil, political, economic, social, and cultural rights, placing persons with disabilities squarely within the international human rights framework. Despite these advances, persons with disabilities and women with disabilities particularly are often ignored in research and development programs. Women with disabilities are generally absent from the UN's Women, Peace, and Security programs; their needs during conflict, in refugee camps, and post-conflict are not met, and they are rarely part of peace-building activities to shape their society post-conflict (Ortoleva, 2010).

2.2.6 Risks and Barriers Amid Complex Emergencies

Disasters often serve to compound existing societal attitudes, and societies for persons with disabilities are devalued, ostracized, or excluded, particularly when there is competition for scarce resources and disaster contexts (Stough & Kang, 2015; Stough &

Kelman, 2018). Additional pre-existing barriers can be attributed to overlapping demographic and social factors like limited access to education, higher rates of poverty and unemployment, food insecurity, and poor housing place persons with disabilities at greater risk. Persons with disabilities are disproportionately more likely to be left behind in emergency responses (UN DESA, 2019), and may also have difficulty accessing humanitarian assistance programs due to societal, attitudinal, environmental, and communication barriers and are at greater risk than their non-disabled peers (Pearce, 2014; Rohwerder, 2017).

Underpinning these barriers is an outdated, yet deeply held view of the medical model of disability. Despite international frameworks promoting the social and rights-based model of disability, many humanitarian actors such as national governments, UN agencies, non-governmental organizations, humanitarian agencies, and local communities operate in line with unconscious biases stemming from the medical model. This leads to one of the principal problems associated with emergency planning for people with disabilities is a lack of interest, involvement, and understanding (Alexander, 2015).

As a result, adapting humanitarian interventions and disaster risk reduction strategies to meet the needs of people with disabilities is frequently seen as prohibitively expensive, time-consuming, and a distraction from providing for essential needs (Pearce, 2014; Rohwerder, 2017; IFRC, 2007). And yet, it is a fundamental ethical principle that people with disabilities have an equal right to disaster assistance programs. There's no justification for relaxing basic principles when disaster strikes. The greatest need at present is the improve coordination among agencies that deal with the needs of people with disabilities (Alexander, 2015)

Failure of humanitarian actors to uphold this principle has resulted in the disruption of social networks, loss and damage of assistive devices, and accessibility of emergency shelters and warning messages, and greater difficulty accessing basic humanitarian needs (Stough & Kelman, 2018). Due to communication or physical barriers, negative attitudes, or other obstacles, persons with disabilities are among the most neglected during flight, displacement, and return. Persons with disabilities face many hurdles in accessing assistance and protection (Shivji, 2010). Additionally, mobility challenges and communication problems may result in not knowing about the risks and finding it harder to flee violence, therefore increasing the likelihood of their being killed or injured (Rohwerder, 2013; Masakhwe, 2004; Hastie, 1997).

For persons with disabilities who flee during a complex emergency, their journeys take, on average, almost twice as long as other non-disabled villagers, putting them at greater risk of further attack and insecurity along the route to safety (Kett & Trani, 2010). Unfortunately, no one knows what happens to these persons with disabilities who have been left behind because humanitarian relief efforts are geared towards providing aid in camps far from those left behind (Rohwerder, 2013). Even worse, a Human Rights Watch report from Uganda stated that 'those who could not [flee] often faced violence' (Barriga, 2010). Separation from or loss of a caregiver can have severe consequences for a person with disabilities, particularly if they are dependent on the caregiver for vital activities such as eating, moving, or toileting (Shivji, 2010). Furthermore, in the chaos of flight, assistive devices such as wheelchairs, hearing aids, communication tools, and service animals are often left behind, limiting independence and increasing the risk of exploitation. The box below provides examples of the risks that persons with disabilities experience when attempting to flee a complex emergency.

Examples of the Risks Persons with Disabilities Experience Fleeing a Complex Emergency

Fula Ali, a 92-year-old woman, told Amnesty International she was trying to leave amid fighting in her village in Ta'iz around a year and half ago. "I was on the asphalt [highway] fleeing the gunfire and fell down and broke myself in three places… People carried me, and we fled and came here," to Sabr Camp in Lahj, she said. She self-identified as having a physical disability and said it was only a few weeks ago that she was able to "somewhat move again", but that she remained reliant on her son to carry her around. "My son carries me everywhere, he takes me in and out of [the tent]. He takes me to the bathroom." (Amnesty International, 2019)

Jalila al-Saleh Ali, said that her husband had struggled with a psychosocial disability (mental health condition) for years; not knowing how to stop him from hurting himself and others the family had resorted to chaining his hands and feet in a room at the back of their house in Ta'iz. "When the fighting happened, we left him next to the house tied up. We don't know if he's dead or alive," she said, breaking down in tears. (Amnesty International, 2019)

He shares the story of a young woman with mobility difficulties from Borno State: "When Boko Haram attacked their community, her two brothers tried to carry her so they could run together." As they tried to lift her, the insurgents killed her two brothers, sparing her life but leaving her traumatised in the process. "Because of such experiences", David explains, "people with disabilities will often tell their families during such attacks: 'just go, if I perish, I perish." (CBM, 2021)

"I hid in the nearby bush and I went back when things calmed down, the same day. I found four bodies on the ground and helped bury them. Among those killed, there was a man called 'Jasper,' who had an intellectual disability, which is the reason why he stayed behind. The military killed him in front of his hut. His body was partly burned, because the military also set his hut on fire. (Human Rights Watch, 2019)

I stayed home until the gunfire stopped in the evening. I remained in the house alone for three days without food or medication. On August 15, some people started returning. That's when they discovered that I had not escaped. They apologized to me and said it was too dangerous for them to return for me.… I

> cannot run when attacks occur. I feel as if I’m a burden to my family, both physically and financially. (Human Rights Watch, 2019)
>
> Persons with disabilities in the former Yugoslavia living in care homes were abandoned by staff unable to evacuate them quickly as the front approached (von Bertele, 2011; Rohwerder, 2013)
>
> Israel where people with intellectual disabilities were shot dead because they did not understand what was occurring and thus did not obey soldiers’ orders (Grove & Myerscough, 2010; Rohwerder, 2013)
>
> In other instances, people with hearing or speech impairments were harassed and arrested at checkpoints because of their inability to express themselves and answer questions posed by the security forces. Their disability was not immediately recognized by the security forces who considered it rather as ‘suspicious behavior’ (Bombi, 2010)

Upon arrival in the camps, persons with disabilities and their families are at risk of discrimination, stigmatization, harassment, neglect, exclusion, isolation, marginalization, and increased dependency, as well as facing problems accessing services (Rohwerder, 2013; Adbi & Matthews, 2009). Displacement often interrupts the provision of essential health services for persons with disabilities – such as chronic disease medication, rehabilitation services, or access to specific health items that are necessary for survival. Additionally, information about distribution times and locations may not be understood by persons with hearing, visual or intellectual impairments; distribution points may be far away or not accessible; and persons with significant weakness may not be able to stand in long queues or carry rations/ relief items (Shivji, 2010). Furthermore, persons with disabilities often remain invisible to registration systems.

Examples of the Barriers Persons with Disabilities Encounter During Displacement

People with disabilities interviewed said that they were unable to make their way to food distribution sites as the location was not accessible or by the time they made their way to the site with assistance, the distribution was already over (Human Rights Watch, 2015).

Jean, a man with a physical disability living in M'Poko camp, said: "My tricycle doesn't fit inside the toilet so I have to get down on all fours and crawl. Initially I had gloves for my hands so I didn't get any [feces] on them but now I have to use leaves." (Human Rights Watch, 2015).

Without mobility aids, many people with disabilities are forced to crawl on the ground to move around, and as a result, they are at great risk of life-threatening infections, such as respiratory problems related to inhaling excessive amounts of dust (Human Rights Watch, 2015).

We disabled people were often unable to run to get food or to stand in line, so it was easy for us to be pushed to the side. For every three humanitarian deliveries we were lucky to get something at one. I saw disabled people dying of hunger out in the open without even a tarpaulin to put over them. It was like we weren't considered to be people." (Human Rights Watch, 2015).

Information in camp settings is generally given through traditional methods, such as announcements and signboards that do not reach visually or hearing-impaired people (Bombi, 2010)

More often than not, temporary shelters, water and sanitation facilities and other infrastructure (temporary health centers and schools, camp offices, etc.) are not accessible for all displaced persons. Uncovered drainage channels, tent ropes, uneven surfaces, steps or narrow doors can impose significant mobility restrictions for persons with visual or physical impairment. (Shivji, 2010).

Essential information about relief efforts (protection systems, distributions, coping mechanisms, health messages, etc.) is often missed by persons with disabilities because they cannot hear broadcasted messages, see posters or leaflets, or understand complicated language. (Shivji, 2010).

The intersection of disability and displacement stands in the middle of two primary legal instruments; the 1951 Refugee Convention and the CRPD. Both asylum seekers with disabilities and refugees with disabilities in camp and urban settings face real challenges in finding durable solutions to their displacement. Some challenges arise from directly discriminatory measures, such as immigration laws that expressly discriminate against persons with medical needs (Crock et al., 2012). In some cases, persons with disabilities are the last to leave because the provisions do not exist for their return and resettlement (Barriga, 2010). In other chronic crisis situations, persons with disabilities often remain in camps or temporary settlements for years, long after most or all of the other non-disabled camp residents have been relocated or have left (Kett & Trani, 2010), abandoned in the camps by their relatives (Rohwerder, 2013; Eriku, 2009; Sarr & Dube, 2010).

The difficulties faced by individuals with disabilities continue and may escalate when they begin the process of returning to their homes. Frequently, information on the return process is unclear and not presented in a manner that can be easily comprehended by all individuals. Additionally, transportation services often fail to accommodate the needs of certain persons, such as using large trucks that are difficult to access and relying on centralized drop-off locations that are located far from their point of origin. This can make it challenging for some to reach their homes. Furthermore, upon returning to their homes, individuals may find themselves in environments that are even more challenging than the camp where they had been temporarily residing.

For persons with disabilities, especially for those who have received appropriate services for the first time while displaced, this can be a major deterrent to resettlement, as was seen during refugee return from Kenya to southern Sudan in recent years (Shivji, 2010). Rehabilitation services that might be in place can also be disrupted by the conflict.

The indirect impacts of violent conflict tend to lead to increased isolation of persons with disabilities (Rohwerder, 2013).

Despite efforts made by humanitarian organizations to offer disability-inclusive programs and activities, few offices of UN organizations and NGOs are physically accessible to persons with disabilities, and the arrangements for meetings and events did not take into consideration the special needs of persons with disabilities unless made by organizations working specifically in this field and who campaign to include people with disabilities in all activities (Bombi, 2010). Compounding inequities make the prospect of livelihoods extremely difficult - especially for women with disabilities whose cash assistance is often distributed to the head of household. For many persons with disabilities, their main source of income comes from begging in the local marketplace.

Women and girls with disabilities face multiple and intersecting forms of discrimination based on their gender as well as their disability, are vulnerable to exploitation and violence, including gender-based violence, and face myriad other barriers to meeting basic needs in humanitarian situations (Women Enabled International, 2021). Women with disabilities are two to three times more likely to experience violence than women without a disability and are less likely to disclose incidents of sexual violence and domestic abuse (CMB, 2022). In addition to double discrimination, the loss of assistive devices, caregivers, and protection networks makes women and girls with disabilities more dependent and at risk of exploitation. They often carry additional burdens as caregivers due to traditional gender roles and, despite experiencing increased levels of sexual and gender-based violence, are often excluded from gender-based violence prevention programs and women's empowerment initiatives.

Women and girls with disabilities also face multiple barriers to accessing food, assistance programs, and lifesaving services, including medical care, accessible information, and safe spaces in humanitarian situations (Humanity & Inclusion, 2015). Being young and female is associated with a unique set of risks, including domestic violence, incest, rape, trafficking, forced prostitution, child marriage, dowry-related violence, and female genital mutilation (Pearce et al., 2016; Todres, 2004). There is a profound silence around the lived experiences of many women with disabilities, which has meant that the violence in their lives is largely invisible and unknown (Pearce et al., 2016).

Examples of the Unique Experiences of Women and Girls with Disabilities Face Amid Complex Emergencies

A young woman with four children, three of whom were affected by severe disability, explained that her family was unable to leave their village, even though the shelling was very close to her house, because they did not have the means to carry the three disabled children. While the rest of the villagers fled, this family remained behind, dug a hole in the ground and hid there for days (Bombi, 2010).

Reports from Nepal also suggest protection issues for women with intellectual disabilities as they are especially affected by trafficking (WRC, 2008; Rohwerder, 2013).

Women with disabilities are particularly vulnerable in humanitarian emergencies, says Obol: “In the camp in Uganda where we work, gender-based violence, sexual exploitation and forced marriages are rampant.” (Young, 2016)

In Handicap International’s research on disability in humanitarian contexts, a third of women with disabilities reporting experiencing psychological, sexual or physical abuse (Young, 2016)

Mobility of women with disabilities in conflict and crises can be ‘curtailed due to fears of abduction, rape or smuggling by human traffickers as well as violence in camps'. Girls with intellectual disabilities in Lebanon were found to have been raped by militias in their area, but their families were too afraid of reprisals and dishonour to react (Berghs, 2015; Trani et al, 2011; Rohwerder, 2017)

Displaced people with disabilities, consulted by WRC across eight countries, reported violence in all contexts, with women and girls with disabilities more likely to report concerns about sexual violence and examples suggesting that those with intellectual or mental disabilities may be most at risk (Pearce, 2014; Pearce, 2015; Rosenberg, 2016; Rohwerder, 2017)

A small 2004 survey in Orissa, India, found that virtually all of the women and girls with disabilities were beaten at home, 25 per cent of women with intellectual disabilities had been raped and 6 per cent of women with disabilities had been forcibly sterilized (United Nations, n.d.).

A refugee woman with a physical disability said, "My daughter has become a prostitute. If I could get some assistance, then our lives would be better." (Pearce et al., 2016)

In general, children with disabilities are more likely to be victims of sexual violence than their peers who are not disabled and three to four times more likely to be physically or emotionally abused (PAHO/WHO, 2012). In a 2018 discussion paper on Children with Disabilities in Situations of Armed Conflict, author Edward Thomas and a core team from UNICEF outline the ways children with disabilities are caught in a vicious cycle of violence, social polarization, deteriorating services, and deepening poverty during armed conflict. Through this discussion paper, Thomas demonstrates how barriers to full participation children face on a day-to-day basis are intensified and compounded when infrastructure is destroyed, and services and systems are compromised and made inaccessible.

Additionally, in a submission to the Committee on the Rights of Persons with Disabilities Article 11 of the CRPD, Human Rights Watch shared reports of parents of children with disabilities struggling to access health care for their children, information about their children's disabilities, and early intervention services for children with developmental conditions and disabilities. Mental health and psychosocial support services were either lacking, generally not inclusive of, or inaccessible to children with disabilities (Human Rights Watch, 2023). This results in the further exclusion and marginalization of children with disabilities and prevents them from accessing schooling, health, and psychosocial support or a means of escape from conflict (E. Thomas et al., 2018). Children with greater impairments face the largest brunt of increased dangers (Rosenthal et al., 2022).

Examples of the Unique Experiences Children with Disabilities Face Amid Complex Emergencies

None of our staff is trained to teach children who are blind, deaf, or have other disabilities," said a staff member working at the school. "So it serves no purpose to let children with disabilities come to this school." Furthermore, temporary schools may not be accessible, teachers may not be equipped or trained to include children with disabilities, and appropriate equipment and materials may not be available (E. Thomas et al., 2018)

According to the UN Office of the Special Representative of the Secretary-General for Children and Armed Conflict (2019) six grave violations of children's rights must be outlined, including the killing and maiming of children; recruitment or use of children as soldiers; sexual violence against children; abduction of children; attacks against schools or hospitals; and the denial of humanitarian access for children (United Nations Office of the Special Representative of the Secretary-General for Children and Armed Conflict, 2019).

DRI investigators observed children tied down, left in beds in near total inactivity, and held in dark, poorly ventilated rooms that are so understaffed that they are enveloped in smells of urine and feces (Rosenthal et al., 2022).

Children with physical disabilities can struggle to flee without assistance and assistive devices such as wheelchairs, prostheses, crutches, or hearing aids. Children who have visual, hearing, developmental, or intellectual disabilities may

> not hear, know about, or understand what is happening (Human Rights Watch, 2022).
>
> I remember hearing conversations when I was [in the hospital]. They thought I was unconscious, but I could hear them talking, saying that I was a 'lost cause' and that it was not worth trying to save my life. I used to think about this often and it made me very upset (Pearce et al., 2016)

Overall, this chapter identifies the normative frameworks at the international, regional, national, and community level, shedding light on the progress made toward advancing disability rights within policy domains over the years. Additionally, the theories of change orient readers to the tools and information that guide humanitarian actors when working with women and girls in humanitarian settings. This includes models of disability, the twin track approach, participatory approaches, universal design, intersectionality of gender and disability, and the heighten risks and harms experienced by persons disabilities in humanitarian settings. Despite the existing body of knowledge, there remains a critical gap in understanding the unique experiences of women and girls with disabilities amid complex emergencies which often go overlooked treated as homogenous. This highlights the ongoing challenges faced by humanitarian actors and DPOs in effectively protecting and providing access to women and girls with disabilities in resource-limited environments like complex emergencies. Embracing an intersectional approach, grounded in the principles of universal design, rights-based frameworks, and meaningful engagement, empowers practitioners to develop capacity for inclusive responses to women and girls with disabilities in humanitarian settings.

Chapter Three: Methodology

The following section examines the current state of disability research amid complex emergencies, and describes the methodology and activities used for in this project for conducting research of secondary sources, online practitioner questionnaires, and semi-structured virtual interviews. As described in the introduction, this project was approved by the University of Denver's IRB (#2026237-1). The study upheld a participatory approach and rights-based framework to disability-inclusive research by engaging disabled persons' organizations and consulting with disabled advocates in the process of developing the online questionnaire and interview questions. This project was rooted in the premise that authentic inclusion requires integrating disabled voices and the experiences of those advocating for, working with, and assisting in research.

3.1 Disability Inclusive Research

Despite emerging guidance on how to foster disability inclusion in research (Farmer & Macleod, 2011), there is still a gap in the literature documenting the practical aspects of conducting such research with persons with disabilities (Harris & Roberts, 2008), particularly in resource-limited and humanitarian settings (Tanabe et al., 2018). As a result, the experiences of persons with disabilities amid complex emergencies or situations of risk go unidentified. For instance, while we may hear about the recruitment of children to extremist groups, we rarely hear reports of persons with Down's syndrome being used as human bombs in conflict (Howard, 2008; Reynolds, 2005). The box below provides examples of how persons with disabilities continue to be overlooked and underserved in emergency contexts.

Examples of How Persons with Disabilities Continue to be Overlooked and Underserved in Emergency Contexts

In Syria, Human Rights Watch reported that children with disabilities experience greater risks during attacks and lack access to basic services due to the failure of humanitarian agencies to sufficiently identify and address the rights and needs of children with disabilities. UN monitoring and reporting paid less attention to children with disabilities, compared with other children. And in the few instances in which children with disabilities were mentioned, data was provided on children who have been injured or “maimed,” but did not frame concerns or responses in the context of the rights of children with disabilities (Human Rights Watch, 2023).

A January 2022 study commissioned by the Office of the Special Representative of the Secretary General for Children and Armed Conflict found that children with disabilities have been overwhelmingly left out of 25 years of UN action to help children caught up in armed conflict (Human Rights Watch, 2023).

The secretary-general’s reports on Afghanistan, the Central African Republic, Palestine, South Sudan, and Syria either did not mention the conflicts’ impact on people with disabilities at all or made only brief reference. Only one of the nine reports on the humanitarian situation in Syria since 2019 mentions the specific needs of people with disabilities and just two mention people with disabilities who had been killed (Human Rights Watch, 2023).

No official international statistics exist on the global prevalence of disability within the persons on the move population; at best, there are estimates. In 2020, an estimated 12 million people in the forced displacement population were persons with disabilities, but the prevalence is likely higher (IOM, n.d.; GMDAC analysis based on UNCHR 2020 and WHO 2011).

Historically, disability research has been conducted on persons with disabilities rather than with them, thereby perpetuating the cycle of injustice and limiting agency. According to Hartley & Muit, published research in the area of disability in the majority of world countries is generally scarce and is traditionally and historically dominated by the quantitative approach. The authors go on to explain that documented research focuses on either the prevalence of impairments, biomedical issues, or the efficacy of interventions in numerical terms. This is problematic for doing disability research on a number of counts (Hartley & Muhit, 2003).

Much of the current body of literature underscores the heightened vulnerability that persons with disabilities face during complex emergencies due to various accessibility barriers. These may be related to physical barriers (Chou, 2004; Osaki & Minowa, 2001; Rahimi, 1993; Van Willigen et al., 2002), communication barriers (White, 2006; Good et al., 2016), comprehension barriers (Gershon, MHS, DrPH, et al., 2013; Takahashi et al., 1997), or pre-existing attitudinal barriers (Stough & Kelman, 2018; Nguyen-Finn, 2012; Scheer & Groce, 1988; Stiker, 1999; Mitchell & Karr, 2014; Kelman & Stough, 2015). It is nearly impossible to deny the disproportionate impact that persons with disabilities experience amid complex emergencies, and it is not difficult to imagine the additional inequities experienced by women and girls.

Prior research has also explored how construction, evacuation, emergency response, and sheltering differ for individuals with a disability and concluded that these inequities negatively affect people with disabilities (Stough & Kelman, 2018). Additionally, the lack of support to prepare, evacuate and recover from a disaster event is a recurrent theme across the literature reviewed (Quaill et al., 2018). Nevertheless, the need to include persons with disabilities in every aspect of research, planning, implementation, and evaluation of programming in humanitarian settings is gaining momentum and will certainly have an impact on future studies.

While statistical research has been useful in shedding light on the harm experienced by individuals with disabilities, the literature frequently overlooks critical analyses of inclusive approaches and the positive outcomes resulting from inclusive humanitarian response efforts for people with disabilities and older individuals. Moreover, there is no evidence relating to the cost of inclusion or cost–benefit analysis on interventions was found, and there was limited evidence on the effective use of data to improve inclusion in humanitarian response (Van Eetvelt et al., 2020).

There are, however, organizations like the Women's Refugee Commission (WRC) that have taken bold steps to advance disability-inclusive research. In a 2016 study[25], WRC employed participatory action research methods to promote equitable inclusion of persons with disabilities in research. Participatory action research methods seek to support empowerment and social justice and transfer power within the research process to participants of the study (Johnson & Walmsley, 2003). Additionally, there has been an influx in guidance notes and good practices published by disabled persons' organizations like Humanity & Inclusion, CBM Global, UNICEF, UNWOMEN, Oxfam, and regional groups like European Disability Forum and Association of Southeast Asian Nations that emphasized the need for a participatory approach.

Although progress has been made in developing tools, training, and in-depth guidance on disability-inclusive humanitarian response since the rollout of UNDIS and the IASC guidelines, there continues to be gaps in operationalizing. Some scholars noted

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[25] Women's Refugee Commission. (2020). Strengthening Networks of Women with Disabilities in Humanitarian Action. Retrieved from https://www.womensrefugeecommission.org/wp-content/uploads/2020/04/Strengthening-Networks-of-Women-with-Disabilities.pdf

that disability researchers seem to agree that there are consistent inequities and disaster service delivery, but their work has primarily been on calling attention to the needs of people with disability rather than developing theory and expanding methodology (Stough & Kelman, 2015). At present, research remains limited to singular events and does not measure the long-term experiences of persons with disabilities across time or multiple disaster settings, thereby hindering comparability. One cause of this could be attributed to external actors operating in silos. It is also noted that there is little evidence of studies that focus on the effectiveness of programs and interventions that support persons with disabilities.

The methodology also tends to be scattered when it comes to research design, limiting access to empirical and disaggregated data. Worldwide, there are differing definitions of disability, and measurement of disability is not straightforward—multiple measurement approaches exist with choices between them influenced by the purpose of the data collection as well as the underlying 'model' of how disability is considered and understood (Palmer & Harley, 2012).

The issue of sample size has also been raised for organizations that provide services and conduct their own research. This becomes an issue when organizations rely on persons with disabilities who access their services to also be research participants because the data is limited to the organization's beneficiaries and does not provide a holistic reflection of persons with disabilities who have been affected. Additionally, the lack of disaggregated data, especially by age, sex, and other factors like displacement, renders people with intersecting identities invisible in data (UN Women, 2021). This limited understanding of the diverse experiences of disabled persons hinders accessibility and heightens stigmatization.

Better data can illuminate how intersecting factors, including age, sex, and gender, affect the displacement experiences of people with disabilities. This involves gathering qualitative information on the specific challenges people face and what they believe would improve their situation (Yasukawa, 2021). To avoid humanitarian data collection earning the dreaded label of being a 'tick-box' exercise, thought must be given to the type and purpose of data collected, with careful planning to ensure the information generated has a pathway to inform action (O'Reilly et al., 2021).

3.2 Qualitative Research

As mentioned, research in the field of disability has been predominantly quantitative in nature, giving little portrayal of what lived experiences of individuals with disabilities are really like (Coons & Watson, 2013; Bollard, 2003; Irvine, 2010; McDonald & Patka, 2012). Though such studies have much to offer, they do not allow for in-depth understanding of the lived experiences of persons with disabilities, let alone, at the nexus of gender and disability. Therefore, the questionnaire and interview questions in this study were designed to be qualitative to illicit anecdotal stories and experiences from participants. Qualitative research necessitates the representation of, and engagement with, people whom the research is designed to assist. Disability research not only seeks to explore populations where lived experience of disability is distinct, but it is also a field where researchers themselves have lived experience (Watharow & Wayland, 2022).

3.3 Composite Narrative

There exists, however, a tension in how best to present qualitative research to convey its findings in a way that is meaningful for others that also meets scientific standards of credibility, dependability, or confirmability (Denzin & Lincoln, 1998; O'Day & Killeen, M). The use of a composite narrative in this project allows the research and results to be presented in a way that acknowledges the intersection of gender and disability amid complex emergencies whilst drawing out more generalized learning and understanding of accessibility in humanitarian settings. In recent years narrative forms of inquiry have become increasingly visible within disability studies (see, for example, Goodley et al., 2004; Marks, 1999; Smith & Sparkes, 2005; Thomas, 1999; Todd, 2006). Narratives thereby help constitute and construct our realities and modes of being. They help guide action and are a psycho, social, and cultural shared resource that gives substance, artfulness, and texture to people's lives (Smith & Sparkes, 2008).

Willis (2019) describes three linked benefits of using composite narratives to present research findings. First, composite narratives allow researchers to present complex, situated accounts from individuals rather than breaking data down into separate categories. Second, they confer anonymity, which is vital when reporting on private deliberations, particularly if interviewees are public figures. Third, they can contribute to 'future-forming' research by presenting findings in ways that are useful and accessible to that outside academia (Willis, 2019). Given that humanitarian actors involve policymakers, government officials, aid workers, and others outside the research community, providing contextualized and personalized accounts via composite narrative builds an understanding of women and girls with disabilities in humanitarian settings in ways that are accessible to non-academic audiences.

3.4 Research of Secondary Sources

Research of secondary sources included a comprehensive search of peer-reviewed articles accessed through Google Scholar and Compass. Compass searches produced a combination of Journal Articles, Print Books, and E-Books. To ensure broad coverage, a range of search terms was utilized, including multiple combinations and variants of "disability", "disaster", and others listed below. Using the results yielded by the initial search, a snowball search method was then used to identify additional studies and reports related to gender, disability, complex emergencies, and qualitative research. Additionally, grey literature was located through humanitarian and development information portals as well as organizational assessments and evaluations conducted by disabled persons' organizations operating in humanitarian settings. Among the reports were those developed by reputable organizations including UNICEF, UNDP, IDA, HI, CBM Global Inclusion, OHCR, OHCHR, IASC, Committee on CRPD, Human Rights Watch, Women Enabled, UN Women, and OXFAM, among others.

Search Terms: Disability, inclusive, organizations of persons with disabilities, complex emergency, disaster risk reduction, women, girls, refugees, displacement, war, conflict, children, humanitarian, qualitative, situations of risk.

3.5 Online Practitioner Questionnaire

The project used existing practitioner networks, alliances, consortiums, reference groups, working groups, membership listservs, and professional social media platforms to recruit participants to complete an online questionnaire of specialists and practitioners working with women and girls with disabilities in humanitarian settings. A list of individuals was also compiled from publicly available online contact information within five major types of organizations: international networks of OPDs and DPOs; international development assistance providers or the aid agencies of donor governments; specialists in international organizations, particularly the United Nations specialized agencies (e.g., UNICEF, IOM); the private sector; and specialists in academia typically found in international studies, disability studies, or gender studies. Additionally, a list of 120 women-led OPDs were contacted by targeted outreach. In total, 2,372 people viewed the project's online flier, and over 300 disabled persons' organizations received an invitation to complete the practitioner questionnaire. Although 51 practitioners accessed the questionnaire, a total of 11 participants engaged with the online practitioner questionnaire.

The project used the cloud-based software platform, Qualtrics, to host the online questionnaire, as it allowed for broad distribution, participant anonymity, and secure data management. A limitation of this platform was the lack of accommodation options, thus potentially limiting participants' accessibility. To gain access to the online questionnaire, participants were asked to confirm self-identification as a "specialist or practitioner" having experience working with women and girls with disabilities in humanitarian settings. Participants who met this criterion were provided with informed consent forms, emphasizing their participation is voluntary, that there is no direct benefit to participation, and that all information will remain confidential.

3.6 Semi-Structured Virtual Interviews

Much like the online questionnaire, recruitment for semi-structured virtual interviews relied on existing practitioner networks and publicly available online contact information. Using snowball sampling, 26 practitioners received targeted outreach and invitations to participate in an interview. A total of 6 interviews were conducted with practitioners and specialists working with women and girls with disabilities in humanitarian settings.

Once participants agreed to be interviewed, they received an electronic calendar invitation, copies of the research protocol and informed consent, and a secure Zoom Meeting Link. Prior to beginning the interview, participants were asked if they had reviewed the informed consent document and if they had any questions before beginning. Recognizing the potentially impersonal nature of virtual conferencing, the principal investigator took a moment to establish a rapport and share what led to an interest in the intersection of women and girls with disabilities in humanitarian settings and pursuing this research project. Doing so helped to create a comfortable atmosphere that encouraged participants to share more freely.

Once all preliminary questions had been addressed, participants were informed that the recording would begin. The semi-structured framework provided avenues for further questioning, clarification, and opportunities for a conversational atmosphere. In the semi-structured interview, the interviewer is allowed to have a certain degree of flexibility and freedom in posing questions (Pretto, 2017). This interview technique has been employed in many studies on disability (Pretto, 2017; Murray et al., 2007; Loeppenthin et al., 2014; Blaylock et al., 2015). Following the process outlined in the research protocol, the interviews were recorded and saved to a password-protected device. Then the files were uploaded to a DU server (Zoom) and deleted from the device. All direct identifiers were removed from the transcription before beginning the analysis. In total, the study yielded a total of 17 participants (n=17). The questionnaire instrument, informed consent, and IRB protocol are included in the appendix.

3.7 Analysis

3.7.1 Reflexive Thematic Analysis

Using primary qualitative data collected from online practitioner questionnaires (n=11) and semi-structured interviews with specialists from cluster sampling (n=6), a predominantly inductive and latent approach was applied to conducting a multi-phased process of reflexive thematic analysis. Reflexive thematic analysis is an easily accessible and theoretically flexible interpretative approach to qualitative data analysis that facilitates the identification and analysis of patterns or themes in a given data set (Byrne, 2022; Braun & Clarke, 2012). As a practitioner, my previous experience in the field of disability enabled me to draw on prior knowledge, making connections to terms and concepts and allowing me to understand what is being conveyed even if it is not explicitly stated. This proved to be important in this study because respondents were based around the world, and depending on the region or context, there is differing terminology related to disability.

Using the six phases of reflexive thematic analysis, developed by Braun and Clarke (2006), the first step of the analysis was becoming familiar with the data by reading both the transcripts and questionnaire results several times to gain a clear understanding of participants' experiences, get a sense of the whole collection, and note initial analytic observations. In addition to codes drawn from the theoretical framework, codes were added if they met the coding rules developed for the project's analysis: 1) terms that came up repeatedly, 2) aligned with previous literature and schools of thought, or 3) stood out as particularly interesting.

Using the list of codes as a guide, each text was examined independently and coded information accordingly. Notes were frequently written to document how codes might connect to each other or link to something important when interpreting the data. To ensure specific points relevant to the codes did get overlooked, a systematic search of the transcripts and questionnaire results was conducted. Codes, however, were not counted. Oftentimes, counting conveys a quantitative orientation of magnitude and frequency contrary to qualitative research. In addition, a count conveys that all codes should be given equal emphasis, and it disregards that the passages coded may represent contradictory views (Creswell & Poth, 2018). Throughout the coding process, a second list of case examples and anecdotal evidence was flagged for later use in developing a composite narrative.

Once the coding phase was complete, the data was collated, analyzed for similarities and differences, and categories built by bringing similar codes together under the same umbrella. Clusters of themes began emerging, and labels were assigned to represent the overall theme. In the process of reviewing themes, each theme was checked against the coded data set to ensure there was a connection between the themes and the raw data, and that the themes reflected the holistic story embraced by the data. Bryman (1989) describes the analytic process as a constant moving backward and forward between data and emerging theoretical notions. Through rigorous coding, multiple iterations of categories and themes, and continuous application of reflexivity, this proved to be accurate.

3.7.2 Composite Narrative Analysis

With qualitative methods, researchers select, interpret, order, and arrange data in order to analyze and present data (Law, 2004; Willis, 2019). The reflexive thematic analysis above, and its subsequent findings, explained in the later section, is one form of analysis. Another form of analyzing and presenting data is through a composite narrative. The creation of a composite narrative involves the blending of stories and experiences of participants into a single narrative of events, and is often crafted to reflect a particular theme or perspective that the researcher wants to highlight (Creswell & Poth, 2018). The main limitation of composite narratives is the burden of responsibility upon the researcher to convey accurate, yet anonymized, portrayals of the accounts of a group of individuals (Willis, 2019). Despite these challenges, the aim of presenting the findings in a composite narrative for this study is two-fold: to shed light on the unique obstacles faced by women and girls with disabilities in complex emergencies and to challenge the dominant narrative by highlighting their ability to make powerful contributions to society if only the barriers to achieving their potential were removed. Through this analysis, a coherent and transparent description of the analysis and process of developing the composite narrative is provided.

The first step of the analysis was to flag relevant stories and anecdotal experiences expressed by participants. A second codebook was then developed using a chronological framework to identify descriptions of pre-existing barriers, flight, displacement, and return. Following a similar process to the previous reflexive thematic analysis, the data was coded and analyzed, then organized into categories by grouping similar data together. Next, the organized data was cross-referenced with case studies and reports collected from grey literature (CBM, Humanity & Inclusion, International Disability Alliance, Human Rights Watch, Amnesty International, and Women's Refugee Commission). Any relevant information was flagged and coded as grey literature. Extensive contextual research was also conducted and collated to ensure the narrative accurately represented the location and events it was portraying.

Using the data collected from online questionnaires and semi-structured interviews, as well as grey literature and contextual research, a preliminary composite narrative was developed. Based on this analysis, the composite narrative was strategically structured to describe the inequities faced by women and girls with disabilities in the first part and use the latter part to describe a potential reality in which the normative conditions were employed.

To ensure accountability of the research, a final analysis of the composite narrative was conducted using the codes: data collected (representing questionnaire and interview responses), grey literature, and contextual research. This final analysis ensured that the narrative was based primarily on the data collected and only supplemented with grey literature and contextual research when necessary. It is important to note that the narrative intentionally avoids including motivations or direct quotes since many of the experiences shared by the research participants were observed rather than experienced first-hand. Additionally, any comments related to emotions are taken directly from their responses.

Chapter Four: Research Findings

The findings of this empirical study provide evidence to substantiate the argument that women and girls with disabilities encounter unique experiences within humanitarian contexts. Moreover, the research finds that the normative conditions enabling DPOs to effectively protect and provide access to women and girls with disabilities amid complex emergencies include an intersectional approach, rights-based framework, universal design, meaningful engagement, and capacity development.

4.1 Normative Conditions

The findings from the thematic analysis, collated with extant research, portrayed common patterns underlying the intersection of gender and disability in humanitarian settings. This study found that disabled persons' organizations most effectively protect and provide access to women and girls with disabilities amid complex emergencies include: (1) specific attention is given to the intersectionality of gender and disability, (2) there is meaningful engagement with women with disabilities, (3) a rights-based model of disability is widely supported, (4) universal design is implemented, and (5) donors invest in grassroots capacity development of OPDs and women with disabilities.

4.2.1 Intersectional Approach

While both gender mainstreaming and, more recently, disability mainstreaming have illuminated important structures of injustice, both movements have failed to address the needs of women and girls with disabilities causing a distinct gap in research in an intersection between and among age, gender, and disability and humanitarian contacts. Field research on violence against women and girls with disabilities or their lived experiences, unique risks, and their specific needs and capacities and humanitarian settings is still very limited (Pearce et al., 2016; Human Rights Watch, 2010; Inclusive Friends, 2015; Pearce, 2015). Many of the questionnaire responses and interviews highlight the issues with data collection and analysis as a result of a non-intersectional approach. With this in mind, intersectionality has served as both the lock and key for advancing the rights and protections of women and girls with disabilities in humanitarian settings.

Primary Findings Underscoring the Need to Apply an Intersectional Approach

- Interview 4: Gender movement is much more advanced. I mean, it's great that it's advanced, but my experience with gender-related work, it doesn't look at women and girls with disabilities or like, for example, older women. But looking at different age groups as well and in other intersectional factors, it's not that advanced. When thinking about gender equity and other DEI efforts, when I look at the disability component, it wasn't there, it was lost. There is a lot of literature on disability in general and some on disabled experiences in humanitarian settings, but then, you know, there's less on the intersection, but there are still specific scenarios and cases of women and girls with disabilities.

- Questionnaire 4: Women and girls with disabilities are not included in the data, therefore not accounted for. Humanitarian actors have no knowledge of proper handling of persons with disabilities. There is no information available, and no consultation conducted for and to the sector.
- Interview 6: When you look at all the structures of identification, women with disabilities are excluded.
- Interview 1: Rehabilitation of healthcare centers or schools that are paying attention to WASH in restrooms and gender sensitivities, but disability not so much.
- Questionnaire 5: On the other hand, some of the least effective ways that DPOs can assess and assure cultural and contextual appropriateness in their response include adopting a one-size-fits-all approach, relying solely on quantitative data, and ignoring power dynamics. Another challenge is the lack of data and evidence on the needs and experiences of persons with disabilities in humanitarian settings.

The application of an intersectional lens is critical for effectively supporting women with disabilities amid complex emergencies for several reasons. Intersectionality acknowledges that women with disabilities are not a homogenous group but possess diverse experiences and identities that result in both unique barriers and skill sets. This approach helps disaster response and humanitarian actors refrain from using a one-size-fits-all model.

Adopting an intersectional lens also challenges practitioners to consider not only gender and disability but also other dynamics such as culture, tradition, class, and displacement status. By doing so, this approach offers a prism through which tailored care can be provided and creative interventions can be identified. The application of intersectionality can enhance advocacy efforts by promoting collaboration and partnership among different groups and organizations with shared objectives. Thereby amplifying the voices and perspectives of women with disabilities and promoting more effective advocacy efforts.

Ultimately, intersectionality serves as both a barrier and an opportunity for effectively protecting and providing access to women and girls with disabilities in complex emergencies. Intersectionality has historically been a barrier because it is the combination of gender and identity that has resulted in data invisibility, heightened risk, and exclusion. That said, it is also an opportunity because, when applied, intersectionality has the potential to address the specific needs of women and girls with disabilities. As its name suggests, intersectionality intersects with every other theme, making it a crucial lens through which practitioners must examine the experiences of women with disabilities in complex emergencies.

4.2.2 Rights-Based Framework

Intersectionality also applies to the unique experiences of women and girls with disabilities and understanding the intangible and tangible barriers they encounter in humanitarian settings. In addition to the barriers that all persons with disabilities in humanitarian contexts face, women and girls are specifically impacted by the effects of patriarchal societies and the medical model of disability.

Primary Findings Highlighting the Need to Adopt a Rights-Based Framework

- Questionnaire 5: People with disabilities may face stigma, discrimination, and negative attitudes from aid workers or other community members, which can hinder their ability to access assistance… Addressing this requires a comprehensive and rights-based approach that prioritizes women's voices, experiences, and perspectives.
- Questionnaire 2: Although persons with disabilities know their rights and have improved access to education and community participation, majority of the population are still viewing disability in a charity and medical perspective.
- Interview 2: I've kind of shifted more to how do you implement a rights-based approach in practice, you know, it doesn't matter if humanitarian actors are able to quote from the CRPD, but they do need to understand what it means in practice to implement a rights-based approach as opposed to a medical approach.
- Interview 1: I discovered the human rights-based approach the CRPD and started to look at disability inclusion from a broader perspective. So, we developed this

strategy based on a human rights-based approach and twin track approach to disabilities and brought in a gender specialist who conducted a workshop just on gender empowerment. We learned more in depth about how to approach gender issues and we began to notice the importance of paying attention to the needs of women and girls in our program.

- Questionnaire 10: Disability is always linked to gods and is seen as a curse or punishment relating to the transgression of a set of prohibitions by individuals or parents. Disability is also considered a social sanction … But due to other factors relating to the status and place granted by society, women would find themselves at the intersection of multiple types of discrimination with each becoming a personal, social and economic incapacitation factor.

A rights-based framework recognizes the inherent human rights and dignity of persons with disabilities and addresses their needs in a comprehensive and inclusive manner. This approach promotes accessibility and equal opportunities, reducing stigma and social exclusion. The CRPD and IASC Guidelines exemplify the impact of this approach. At the international level, commitment to a rights-based framework has increased the participation of OPDs and understanding of tangible and intangible barriers faced by persons with disabilities in complex emergencies.

By combating beliefs and assumptions that underpin attitudinal, social, economic, and institutional barriers, a rights-based approach addresses the specific challenges that women with disabilities face. When embraced by disabled persons' organizations, women with disabilities are seen as valued members of the community and agents of change rather than recipients or beneficiaries.

4.2.3 Universal Design

In line with extant research, the data suggests that in addition to attitudinal, social, and institutional barriers, women and girls with disabilities are exposed to particular harms often related to gender-based violence, poor WASH facilities, and access to information in general. These practical and tangible barriers pose some of the greatest challenges for DPOs in providing access to women and girls with disabilities amid complex emergencies, particularly in displacement.

Primary Findings Highlighting Barriers to Accessibility and the Need to Apply Principles of Universal Design

- Interview 1: Transportation is not accessible even when available. It's not comfortable for what women and girls to take for fear of exclusion and violence, especially in crowded areas and crowded settings. Also fear of being left behind or left till the end of the of the process. Or, not being consulted, being late in coming back, especially if they are commuting from remote areas. Along those same line, another concern is the access to WASH facilities, especially if they are going to somewhere far away.

- Interview 4: Information about GBV services often just doesn't reach women and girls with disabilities. For the same reason. You know, girls are out of school. Information isn't accessible.
- Questionnaire 10: Poor sanitation in slums where the refugee women with disabilities live; Inadequate training in life skills; Communication barriers due to lack of Sign Language
- Questionnaire 2: The dignity and self-esteem of women with disabilities were always at stake, especially those with severe mobility limitations, psychosocial disabilities and children with disabilities. Panic during disasters and lack of disability awareness and sensitivity especially in geographically isolated and disadvantaged areas.
- Questionnaire 8: After the devastating earthquake 2015 women with disabilities face difficulty to take emergency support such as not temporary shelter, WASH, food and other essentials support including access the information. For instance, toilet is not accessible, specials attention on counseling, sign language interpretation, assistive device which they lost and not getting immediately.
- Interview 2: You know, in many settings, children with disabilities are not in school. Schools may be the safe places in certain emergencies, and schools are also the places where a lot of humanitarian assistance might be delivered, such as, you know, school feeding or nutrition interventions, vaccinations. In some settings, people with disabilities being actually targeted for violence, they can be more at risk of certain things like recruitment of child soldiers because of

perceptions and the value the lack of value placed on children with disabilities, and of course, the lack of accessibility humanitarian assistance.

- Questionnaire 6: Girls and women with disabilities are the most affected! While most of the challenges are common for other people with and without disabilities, girls and women with disabilities are for example particularly affected by droughts whereby with climate change and water shortage it hard to fulfill the expected gender roles (cooking, house sanitation, washing etc.) yet they cannot travel for distances to fetch water that creates situation of conflict and even being abandoned their husband.

Implementing universal design in humanitarian settings can significantly benefit women and girls with disabilities by promoting accessibility, inclusion, safety, and empowerment. Designing accessible spaces and programs that account for alternate forms of communication like using sign language interpreters, braille, or plain language infographics, or promoting physical access like building ramps instead of stairs, using door handles instead of knobs, or ensuring secure WASH facilities. When DPOs design environments, products, and services that can be used by everyone regardless of their abilities, it enhances the social inclusion of women and girls with disabilities. Additionally, universal design increases safety and security for those at risk of abuse, fosters independence and autonomy, and minimizes their reliance on others.

4.2.4 Meaningful Engagement

The involvement of OPDs came up several times throughout participant interviews and questionnaire responses, many highlighting the importance of meaningful engagement with OPDs to ensure that their participation is less tokenizing and more focused on power-sharing. Others noted that while OPDs are essential, many are not representative of women with disabilities and often neglect their unique needs. This is particularly important because the data suggests that women are more likely to engage when they see themselves reflected in humanitarian workers and advocacy groups, as it reduces fears of being misunderstood or misrepresented. One participant repeatedly emphasized that the localization of OPDs and safe spaces where women can have their voices heard has proven to increase empowerment, build trust, and protect dignity.

Primary Findings Underscoring the Importance of Including Women with Disabilities to Achieve Meaningful Engagement

- Questionnaire 4: Many of the gaps can be strengthened through meaningful participation of the organizations. It is essential for policy makers, decision makers and program implementers to make a conscious effort to make us more visible and heard. To do so, channels should be opened, and minimum accessibility requirements should be observed to ensure that our participation is meaningful and not tokenistic in nature. No one should talk on our behalf as we can confidently speak for ourselves. Consulting them is the key and listening to their voices. - Inclusion of the sector not just an "after thought" - meaningful participation bridges meaningful change.

- Questionnaire 2: International policy is only effective if there's an existing local policy support. The best thing is using international policies as reference in the development of local laws. We partner with international agencies to develop and implement programs that will demonstrate participation of persons with disabilities in advocating for inclusive policies and their inclusion in local decision making. Providing women with disabilities to have self-awareness will increase confidence, communication skills and tell their stories without inhibition, will advance social integration for displaced women.
- Interview 5: There must be representation. There has, you know, to be someone who understands, whether it's the localized context or the context of disability and accessibility.
- Interview 4: Cultural and contextual appropriateness will be best achieved if DPOs are from the same area, respecting the culture and has deep understanding of customs, traditions, and language. The least effective is the contrary. I think having local people on staff, partnering with local organizations, particularly representative organizations like OPDs and women-led organizations. Also, you know, having committees of local populations, both host and displaced, and having those committees have a meaningful role in decision, making and planning is most effective.

- Questionnaire 5: By working together with local organizations and persons with disabilities themselves, they can help to create more inclusive and effective humanitarian responses.

Effective humanitarian response requires partnership and power sharing among international actors and the local community. More recently, there has been movement towards localization because of the importance of understanding the local context, including the customs, traditions, and social and political dynamics of the affected community. When international actors harness the knowledge, resources, and capacities of local actors, humanitarian response is more effective and appropriate. For this reason, many respondents noted that international presence following a disaster should be minimal.

One compelling finding from the data is the frequent reference to informal organizing by women with disabilities in humanitarian settings. This suggests that in the absence of specialized assistance, women with disabilities found ways to mobilize resources to meaningfully engage with one another. One participant emphasized women with disabilities possess power, agency, and a desire to participate in humanitarian response; however, they are not typically perceived as valuable assets. In many ways, this finding resonates with Cedric de Coning’s work on Complexity Theory for Peace and Conflict Studies, which proposes external actors can assist and facilitate this process, but if they interfere too much, they will undermine the self-organizing processes necessary to sustain resilient social institutions (de Coning, 2020).

4.2.5 Capacity Development

Despite progress at the international level in educating and raising awareness about the rights of persons with disabilities, there remains a significant knowledge gap with humanitarian practitioners and the public. With international law established, efforts must be made to link policy to action. According to questionnaire responses and interviews, a large piece of this can be attributed to capacity development - specifically directing resources towards training and awareness raising and ensuring financial budgets account for disability.

Primary Findings that Emphasize the Need for Training

- Interview 2: There needs to be some really dedicated resources put in basically people. Bodies that are doing some training, documenting good practices, establishing procedures, linking with OPDs. GBV training today to frontline workers also needs to include disability, accessible information and reaching out proactively to women and girls with disabilities through OPDs or through home visits. In this one example, there is a case of a young woman with a disability who had been sexually abused multiple times, and the police and others responding to it kept telling me they just don't know what to do. Where do they keep her? How do they talk to her? How do we know she is telling the truth? In many places they do not believe claims of abuse against women with disabilities because they don't think they are worthy of being touched.

- Questionnaire 6: For organizations of persons with disabilities to be more effective they need quality training on emergencies preparedness, management, and reintegration to be equipped with appropriate knowledge and equipment. Priority actions might include training their staff and partners on disability, ensure they have appropriate policies inclusive of disabilities and consult and work with organizations of persons with disabilities. This will require them to have reasonable accommodation budget to respond to this. The lack of inclusive policies and strategies and with limited knowledge among the stakeholders are the main gaps. Capacity development must focus on building knowledge and technical capacity of the organizations as well as awareness among the community including persons with disabilities and their organizations.
- Questionnaire 5: One of the main challenges is the lack of understanding of disability issues among humanitarian actors, including international organizations, governments, and local organizations. The response capacities of local organizations can be strengthened in several ways. One approach is to provide training and capacity-building support to staff, volunteers, and leaders of local organizations. Aid workers who are trained in disability inclusion and awareness can help to ensure that people with disabilities are identified and included in humanitarian response efforts.

Training and preparedness can be instrumental in promoting the well-being of women and girls with disabilities in humanitarian settings. The lack of awareness often stems from fear rather than deliberate avoidance. Therefore, it is important to have a comprehensive and holistic approach to trainings that includes targeted outreach and promoting awareness at all levels. This should not be limited to DPOs but encompass all stakeholders, including policymakers, local police, social services, emergency responders, humanitarian actors, frontline workers, direct service providers, families, and caregivers. When humanitarian actors are educated about the experiences of women and girls with disabilities, it challenges negative stereotypes and equips practitioners with the knowledge and skills to respond appropriately and safely. The best way to obtain specialists and provide meaningful training is to invest in building the capacities of women and girls with disabilities to claim their rights and use their agency and experience to become strong advocates. The rise in online education, training modules, and accessible technology could offer a solution that is high impact and low cost.

The link between capacity development and funding is clear. However, disability-related funding lines are rarely included in humanitarian and development budgets. When they are, it is often directed to quick accommodations or dispersed too broadly to make a meaningful difference. The amount of money that trickles down to the local level and impacts persons with disabilities is minimal. Several participant interviews indicated that one of the primary concerns for women with disabilities is livelihood, while many questionnaire responses emphasized the pressing need for assistive devices. Directing funds towards programs that support women and girls with disabilities in humanitarian settings can alleviate these concerns. Unfortunately, this is not happening enough.

Primary Findings that Recognize the Need for Disability-Inclusive Financial Budgets and Investment in OPDs

- Interview 5: Right now, you don't have to show how much your money is contributing to a disability. All you have to do is follow the money and it will show there is no disability.
- Interview 4: It is still a top-down approach. Even the ones which are supposed to be doing a great job on disability inclusion and promoting a rights-based approach. They take money from bigger agencies. They put that money in their country. That country hires their local NGO. That local NGO is hiring a DPO. That DPO is expected to do advocacy work and implement activities. They cannot use a super complicated reporting template. Yet there is still this approach of all you report to me. We talk about partnerships, but you end up giving little money to the organizations that need it. The money needs to go more to the local organizations.
- Questionnaire 5: Policies that prioritize the inclusion of people with disabilities in humanitarian responses and provide funding to support disability-inclusive programming can improve access to services and support for people with disabilities.
- Interview 2: There's almost very little attention to is the specific services side of things, and primarily assistive technology it's very high cost. It's often not included in humanitarian budgets. People affected by humanitarian emergencies often don't have access to national systems or national systems are no longer

functioning, you know, in emergencies. So, the traditional form of support is gone.

- Questionnaire 6: It's often not included in humanitarian budgets. The most challenging stage is for temporary displacement when stakeholders are not interested in making costly interventions and adjustments to accommodate the needs of persons with disabilities. This will require them to have reasonable accommodations in their budget to respond to this. Even when people understand the rights of persons with disabilities, the change in practices to protect and accommodate their rights is still challenging because of some irrelevant excuses that they lack budget, it is very expensive to accommodate them etc.

Countries that benefit from neoliberal policies have a responsibility to reflect on the impact of such policies on the countries most affected by complex emergencies, including the vulnerable populations within those contexts. There is an opportunity for such donors to address the gap in funding by requiring disability inclusion funding lines in proposals as a prerequisite for aid. When international donors require disability inclusion, it motivates humanitarian actors to rethink their response efforts and consider how to effectively meet the needs of women and girls with disabilities. Additionally, when funds are specifically directed to OPDs, it empowers and enables them to address real needs in their local communities in a timely manner. Similar to the issue with data, history is evidence that without specific attention to gender and disability, budgets will continue to overlook the intersection.

4.2.6 Model of Normative Conditions

A review of the recurring themes that emerged from the data made it clear that these themes are all interconnected and intertwined and there are several ways the various theories and approaches can be represented. Below is a cycle of how each theme naturally leads into the next.

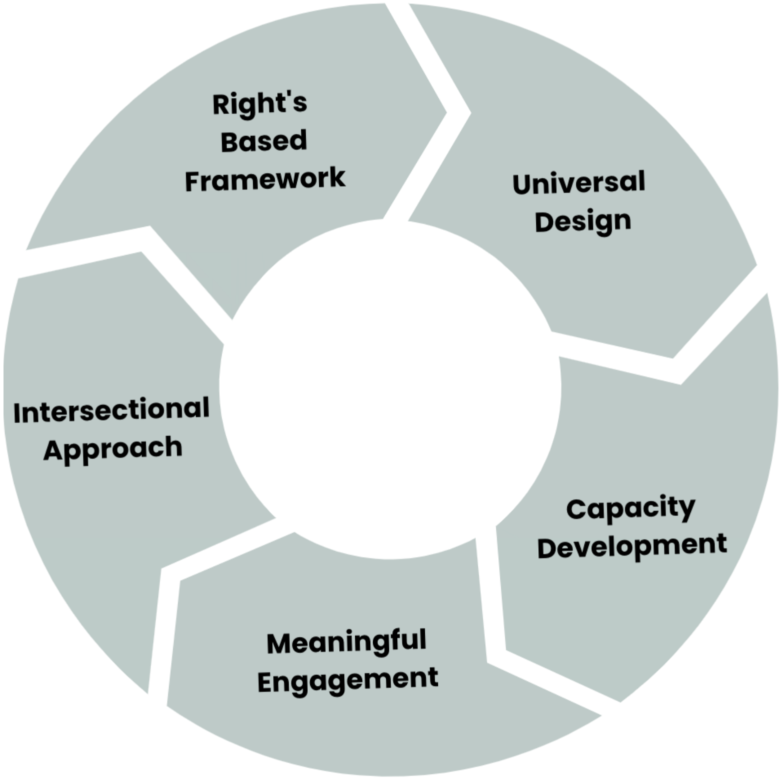

Figure 1: Model of Normative Conditions to increase effectiveness of disabled persons' organizations.

At the apex of the model lies the ultimate objective of embracing a rights-based framework to address the intangible barriers that underlie existing inequities. Tracing the model backward, we recognize that an intersectional lens must be applied to realize this rights-based approach. Our data reveal that such a lens necessitates the meaningful engagement of women and girls with disabilities, and such engagement, in turn, calls for the local development of capacity. As part of capacity-building, we must remove tangible barriers to accessibility, which can be achieved through the implementation of universal design. To generate support for universal design, it is crucial to adopt a rights-based framework, thereby bringing us to the top of the cycle.

One might instead choose to follow the arrows indicated in the cycle, recognizing that by adopting a rights-based framework, a DPO is more likely to utilize universal design principles when developing safe spaces and programs. Such accessibility enables organizations to build local capacities and foster meaningful engagement with women and girls with disabilities. Incorporating the voices of women and girls with disabilities will promote an intersectional approach, which inherently supports a rights-based framework.

Regardless of the direction in which the cycle flows, this model tackles the entrenched ableism in the current international humanitarian system and offers a roadmap to move forward by recognizing the dignity of each human being before their disability. While this model focuses on women and girls with disabilities, it can be transferred to any marginalized group affected by complex emergencies. When we recognize that disability rights are human rights and work to remove barriers, we are all one step closer to freedom.

4.2 Composite Narrative

The findings of the second thematic analysis revealed common experiences unique to women and girls with disabilities during complex emergencies, including pre-existing barriers, and experiences during flight, displacement, and returning home. Women and girls with disabilities have historically lacked representation in disaster discourse, limiting progress to addressing their specific needs. Highlighting these common experiences helps humanitarian actors understand the gender and disability nexus in humanitarian settings and how to effectively respond. Below is a table that identifies common experiences that women with disabilities share at various levels of complex emergencies.

Table 1: Common Experiences of Women and Girls with Disabilities Amid Complex Emergencies

Pre-Existing Barriers	Patriarchal Tradition Gender Roles Stigma/ Negative Attitudes/ Shame Medical Model Risk of Violence/ Abuse Limited Access To Education, Transportation, Healthcare, etc. Dependent On Family Social Isolation Child Marriage
Flight	Abandonment Burden Increased Pain/ Discomfort Fear Reliance on Others Inaccessible Transportation Responsibilities of Motherhood
Displacement	Unsanitary WASH Facilities No Identification Inaccessible Food Distribution Depression Responsibilities of Motherhood Limited Accessible Devices

Return	Concern for Livelihood Gender-Based Violence No Accommodations No Resources for Disabled Persons Reliance on Programs/Interventions Need for OPD Uncertainty Women-Led Initiatives Empowerment Programs Peer Counseling Concerns for Livelihood Community Building

These common experiences are woven together in the composite narrative to create a vivid portrayal of a young woman with a physical disability living in Syria following the events of the Arab Spring. Syria was thoughtfully chosen as the backdrop for this narrative for several reasons: 1) the inclusion of study participants with firsthand knowledge or experience in the region lends authenticity and credibility to the accounts shared. 2) Syria has been affected by several complex emergencies, including war, social and economic crises, the COVID-19 pandemic, the Cholera outbreak, and most recently an earthquake underscoring the importance of shedding light on women with disabilities experiencing these crises. 3) There is ample grey literature focusing on Syria from various NGOs that bolsters the research and supports its findings.

The composite narrative begins by painting the picture of what life is like for a woman growing up with a disability and experiencing many of the pre-existing barriers identified in the table above. It then provides an overview of the challenges that a woman with a physical disability might face when fleeing to safety, including her reliance on others, the strain that is placed on some relationships, and her internal battles. The narrative goes on to highlight the barriers that women with disabilities encounter during displacement, involving physical barriers, limited access to services and resources, discrimination, and the prevalence of gender-based violence.

As the narrative progresses, it shifts from portraying barriers, despair, and isolation to embracing themes of access, empowerment, and envisioning a brighter future. By applying the model of normative frameworks, the narrative serves as an exemplar of how the lives of women with a disabilities can be transformed when specific attention is given to the intersectionality of gender and disability, there is meaningful engagement with women with disabilities, a rights-based model of disability is widely supported, universal design is implemented, and donors invest in grassroots capacity development of OPDs and women with disabilities.

Through its careful construction, the primary objective of this composite narrative is to help readers understand the experiences, challenges, and opportunities of women with disabilities in complex emergencies. By highlighting the intricacies of the protagonist's life, the narrative sheds light on the specific barriers faced by women with disabilities during times of crisis and displacement and invites readers to connect on a personal level. In doing so, the narrative cultivates empathy and encourages readers to recognize themselves in the storyline and circumstances Sarah found herself in. Ultimately, by raising awareness to the plight of women and girls with disabilities in humanitarian settings and showcasing the benefits to applying normative conditions, the narrative seeks to promote the rights, dignity, and capacities of women with disabilities.

Composite Narrative

Sarah is a Sunni woman in her late twenties who grew up in Zabadani, Syria, a town in the mountainous western Qalamoun region near the Syrian Lebanese border. When Sarah was two years old, her parents took her to a local health clinic due to concerns about her development and her struggle to learn how to walk. Doctors did not take long to diagnose Sarah with a congenital disease that would affect her mobility for the rest of her life. Before leaving the clinic, doctors fitted Sarah with elbow crutches and told her parents there was nothing more they could do. One doctor even told them she would be better off in an institution.

Initially, Sarah's parents were devastated by the news. In their community, negative attitudes and superstitious beliefs towards women and girls with disabilities were common. They could not help but feel shame for Sarah's condition and questioned if it was their fault. They also knew what happened to women with disabilities and feared that Sarah would be subjected to violence or abuse.

During her formative years, Sarah struggled to establish connections with other children her age due to the challenging terrain surrounding her town. Flanked by the imposing Mount Senir and Jabal Al Shaqif mountain ranges, she found navigating the steep ridges and narrow, rocky paths on her crutches difficult. Given that accessible transportation was limited, she only traveled when someone in her family could accompany her.

Sarah was grateful for the brief time she attended school alongside her older brother, Nael. However, when Nael began attending secondary school, the journey proved too hazardous for Sarah to undertake alone. To supplement her education, Sarah's mother took on the task of homeschooling, using Arabic folklore and poetry to teach. While tending to their small orchard, Sarah would listen to enchanting tales of magic lamps and thrilling adventures, allowing her to escape into a world vastly different from hers.

At 14, Sarah's father informed her she would marry his friend Hari, as a favor to her father. In the patriarchal society in which Sarah lived, Hari was the head of their household and expected Sarah to stay home and raise their daughter, Zaya. Although the town of Zabandani was close to the bustling city of Damascus, Sarah, like other women with disabilities, refrained from engaging in public activities due to her condition. This furthered her isolation from society and dependence on others.

In the summer of 2012, Sarah and her family heard rumors of an impending civil war and the brutal attacks directed by President Bashar al-Assad. Not knowing what to expect, they decided that when the shelling began, Hari would flee with her parents and 2-year-old Zaya to the nearby village of Bloudan. They feared that Sarah would place the family in danger due to her condition, so they left her at the family orchard with her older brother Nael and hoped that everything would turn out okay.

One night, Sarah and Nael awoke to the earth-shattering sound of bombs exploding and gunfire blasting. They decided to flee without packing their bags or attempting to go to the bus station. Sarah could not keep up with Nael's pace, so he resorted to carrying her. Despite the danger, hunger, and other challenges they faced, Sarah and Nael were able to join the thousands of refugees escaping to Bloudan. There, they reunited with Hari, Zaya, and Sarah's parents in time to join the caravan of refugees crossing the border into Lebanon.

Throughout the journey, Sarah did her best to soothe her daughter and not be a burden on her family though her elbows bled from the crutches and her feet felt like cement blocks. Sarah was most afraid at nighttime, because that is when she felt the most vulnerable. While she and Hari had been apart his behavior towards Sarah shifted from care to resentment.

In the days leading up to the caravan's arrival at the Wavel refugee camp in Lebanon, Hari, Sarah, and Zaya were separated from Nael and her parents. Sarah had hoped that their arrival at the camp would bring some relief, but instead, she was consumed by a sense of utter desperation. The camp was severely overcrowded and lacked sufficient resources to support the number of people there.

Adding to her distress, Hari's behavior had become increasingly erratic, leaving Sarah without reliable support. Sarah also had no personal identification since no one found it worthwhile to help her get a national ID card. Without Hari, she was undocumented and would have remained unreported at the camp.

Once inside Wavel, Sarah faced countless barriers, and the thought of navigating the tight corridors and muddy walkways with her crutches while carrying Zaya on her back seemed daunting. She was, however, grateful to still have her crutches, as most mobility devices ended up damaged, stolen, or lost on the journey.

Despite having her crutches, Sarah was unable to travel to food distribution locations, making it difficult for her to provide for Zaya. Sarah felt completely adrift without the support network that she had grown to rely on and was disheartened to find no signs or acknowledgment of accommodations for persons with disabilities in the camp. Even basic facilities like latrines and WASH facilities were inaccessible, forcing many other women with physical impairments to create their own. Given the unsanitary conditions, cramped living spaces, and the constant threat of abuse and disease, the conditions in Wavel were far from ideal.

Sarah often felt depressed and hopeless. Her concerns grew after hearing rumors that some husbands abandon their wives due to injury or physical disability, and she worried the same might happen to her. Hari was her source of financial stability, and she was never taught the skills to provide for herself beyond the confines of the orchard. Sarah also carried the burden of responsibility to care for Zaya and ensure she was safe. She had endured verbal and physical abuse from Hari for months but did not have access to resources or avenues of support. Sarah also feared someone might try to take Zaya away from her due to cultural beliefs that women with disabilities are not worthy of caring for their children.

One day, volunteers from the UNDP came to Sarah's temporary shelter. Initially, Sarah did not trust or want to speak to them. However, as time passed, she observed how the volunteers listened attentively to other women and took detailed notes. Eventually, Sarah agreed to speak with one of the female volunteers. Before leaving, the woman asked for Sarah's permission to connect her with a local organization of persons with disabilities. Sarah found it hard to comprehend that there were organizations led by persons with disabilities and agreed.

Weeks later, Sarah was visited by an OPD representative and was surprised to observe that the woman was blind. As they spoke, Sarah realized how much they had in common and felt that, for the first time in her life, someone understood her experience. The representative invited Sarah to a meeting with other women in the camp who had disabilities, where she could learn about her rights under the CRPD and receive information about gender-based violence. She was grateful that the volunteers working with the OPD understood the need to also provide daycare services. By hearing the stories of other women and sharing her own, Sarah gained newfound courage and was empowered to envision a life for herself and Zaya beyond Wavel.

As time went on, Sarah grew in self-advocacy- both at home with Hari and in the camp when she faced discrimination due to her disability and gender. Through her volunteer work with the OPD, she became aware of the medical mistreatment that some women in the camp experienced. When a new health clinic opened, Sarah organized a workshop for the doctors and aid workers. She shared her experiences with doctors and the need for gender sensitivity. Her efforts raised awareness and promoted inclusivity within the healthcare system.

Sarah's return to Syria marked a turning point in her life. With the help of the OPD, she safely left Hari, obtained formal identification, opened a bank account, and secured a small apartment in Damascus that was designed with accessibility in mind. The inclusion of a ramp, motorized door, and elevator made it easier for Sarah and Zaya to move around independently. Living in the city also provided them with greater access to resources and opportunities, and as the social dynamics of the community shifted in the wake of the war, Sarah found herself in a more equitable environment where women were empowered to take on more visible roles.

Sarah was recruited to work at a women-led civil society organization in Damascus renowned for its conflict resolution and violence prevention efforts. The organization, Mobaderoon, applies a rights-based framework and recognized the importance of having disability representation on their staff. Through the formation of local committees comprising community leaders, teachers, civil society activists, and ordinary residents, Sarah played a vital role in promoting social cohesion and reducing tensions in her community. Her intersectional lens of gender and disability highlighted gaps and opportunities to remove barriers throughout the processes of rebuilding and pave a way that is accessible for everyone.

Sarah also discovered that poetry was a therapeutic outlet for her and used it to express the stories of other women with disabilities she met at Wavel, capturing the beauty of their journeys and the challenges they faced. Following in the footsteps of her mother, Sarah continues to educate others through the power of storytelling.

Chapter Five: Conclusion

5.1 Discussion

The discussion section offers a comprehensive analysis and interpretation of the research findings, illuminating the intersection of disability, gender, and complex emergencies by exploring the implications of the study's results, identifying limitations and challenges encountered, and proposing recommendations for future research and practical applications. By comparing the research findings against existing literature, the discussion highlights what makes this study unique and introduces the unanticipated discovery of using technology to remove barriers and promote inclusion in humanitarian settings.

A limitation of previous literature is that disability is frequently treated as a homogenous demographic group (Stough & Kelman, 2018). While the intersection of age, gender, and disability has been documented by disability and feminist theorists (Pearce et al., 2016; Hughes et al., 2005; Watson et al., 2004), the implications for women and girls in humanitarian contexts remain largely unreported. This research study investigated the intersection of disability, gender, and complex emergencies, specifically how DPOs can effectively protect and provide access to women and girls with disabilities in these situations. Using qualitative research methods and conducting reflexive thematic analyses, this study harnessed information provided by practitioners and specialists to identify normative conditions that inform decision-making and improve outcomes for women and girls with disabilities in humanitarian settings. This project also gives voice to the unique experiences that women and girls with disabilities encounter amid complex emergencies through its composite narrative.

The findings of a 2022 report by the International Disability Alliance, OPDs report that their participation is far from being meaningful and call for investments to build their capacities and opportunities to engage (IDA, 2022). In addition to importance of including OPDs as key stakeholders in the planning, implementation, and monitoring of humanitarian response, the findings of this study stress the need for increased representation of women with disabilities on staff and in leadership in such organizations. Unlike previous studies, which are typically quantitative or involve beneficiaries, this project investigated the conditions that enable DPOs to be most effective, providing a valuable perspective for future program development. This study's interest among scholars and practitioners is significant and underscores the critical gap in the literature and the need for research on the intersection of gender and disability in complex emergencies.

Another element that separates this study is the deliberate and comprehensive approach to disability inclusion in the research design. This was demonstrated in the strong commitment to reflexivity and ensuring that a participatory approach was incorporated throughout the study, making it a leading example of incorporating inclusive practices in research design. Such inclusive strategies and lessons learned have the potential to be applied across a wide range of other fields involving human subjects research. The research design also accounted for broad distribution and question development. The data was enriched by involving participants from around the world in various levels of leadership, enabling us to draw valuable commonalities from various perspectives. Moreover, the broad nature of the questions also helped to avoid issues related to defining specific disabilities or classifications by designing the questions to discuss disability more generally.

The findings of this study have stressed the need for more qualitative research that places the experiences of women and girls with disabilities at the center. This, however, will require a radical reorientation of the traditional power dynamics in research, enabling persons with disabilities to act as participants and researchers. Such a shift will demand significant time and effort, but it is a crucial step toward including the voices of marginalized and at-risk groups in research. Future disability-inclusive research should also examine the effectiveness of program interventions in humanitarian settings over time and address a broader range of gender identities, including gender diverse and LGBTQ+ individuals.

The research raises awareness about the unique challenges that disasters pose to women and girls with disabilities, offers insight into the factors that enable DPOs to effectively support them in crisis, and strategies to empower women with disabilities share their knowledge and skillsets. Moreover, the study draws attention to the ableism within the current humanitarian regime and calls for collaboration among international instruments such as the CRPD, CEDAW, and CRC. Finally, this study underscores the power of personal narrative, showcasing the impact that hearing individuals' stories and lived experiences can have.

5.1.1 Using Technology to Remove Barriers

An unexpected yet significant discovery emerged from the research findings, revealing the transformative potential of leveraging technology to remove barriers and enhance accessibility for women and girls with disabilities in humanitarian settings. Conflict brings with it a significant potential for change, as it destroys old systems and can bring in new ideas and funds, which offers the opportunity to change attitudes and remove disabling barriers (Rohwerder, 2013; Hastie, 1997), creating greater resilience amongst persons with disabilities. Behind every crisis lies the opportunity to advance disability-inclusive development that benefits society in the long run. One way to do this is harnessing advancements in technology to improve accessibility, communication, social inclusion, disaster response, financial freedom, and resource allocation for both women and girls with disabilities, as well as humanitarian workers amid complex emergencies.

The data indicated near consensus that women and girls with disabilities need timely access to assistive devices, information, and cash relief. Below, I outline various innovative technologies to meet this urgent need. I also include emerging technologies that have the potential to impact the humanitarian field as they develop.

- **3D Printing:** 3D printing has the capacity to mass produce affordable prosthetics and assistive devices like white canes, customized braces, or key parts of mobility aids that have been lost or damaged during the emergency. The use of 3D printing in humanitarian contexts allows international agencies to bypass issues with the supply chain, cut shipping and transportation fees, and provide assistance to beneficiaries on-site in real time. 3D printing has enormous potential to increase the independence and autonomy of women and girls with disabilities amid complex emergencies.

- **Blockchain Technology:** Blockchain technology can provide protected and transparent transactions that can be used across multiple stakeholders in humanitarian contexts, offering agency and independence to women and girls with disabilities amid complex emergencies. Such technology can be used for personal data management, including medical records and identity materials. This is critical as identification is often necessary to receive aid, register for refugee status, and participate in civic duties like voting. Blockchain also has the potential to support cash relief programs by allowing cash to be transferred without needing a centralized system like a bank. In addition to the direct support blockchain offers beneficiaries, it can also help humanitarian actors address issues with the supply chain, distribution of aid, donation tracking, cash disbursal, and collaboration in relief operations.
- **Smart Contracts**: Like blockchain, smart contracts can enable women with disabilities to take ownership of documents like land agreements or business deals without the barriers typically associated with accessing legal and financial services. This can be especially helpful for safeguarding assets during emergencies.
- **Biometrics:** Biometric technology can assist women with disabilities in identifying themselves using alternate methods like facial and voice

recognition or fingerprint technology if they are not able to produce passwords or codes by memory.

- **Information and Communication Technology (ICT):** ICT encompasses a wide range of tools ranging from early warning systems that help persons with disabilities flee crisis to telemedicine that makes healthcare accessible to women with disabilities who cannot travel long distances. Additional tools like screen readers, voice recognition software, and apps like Be My Eyes and Proloquo2Go allow persons with disabilities to perform daily activities. At the same time, accessible communication platforms like WhatsApp and Zoom enable women with disabilities to build support networks and access information about sensitive topics like GBV.
- **Solar and Wind Power:** It is critical for many women with disabilities to have access to reliable sources of electricity amid complex emergencies, and too much reliance on power grids increases their vulnerability. Alternate sources of power, like solar and wind, can generate electricity for necessary medical equipment like ventilators and mobility aids like powered wheelchairs and elevators.
- **Digital Twins:** Digital twins can be used to simulate disasters and emergency situations, allowing international agencies to improve the efficacy and efficiency of disaster response efforts by developing and testing response plans in a safe and controlled environment. By collecting and analyzing data from the virtual environment, international agencies can identify areas where

interventions work well and how to allocate resources like food, water, and medical supplies. They can also simulate different scenarios to provide training to humanitarian workers and develop the skills to respond effectively.

- **Starlink:** Access to the internet is especially important for women with disabilities in humanitarian settings as it allows them to use many of the abovementioned ICTs. It also opens avenues to participate in online education and training that they may not otherwise have access to. Unfortunately, traditional internet infrastructure is often disrupted or non-existent during complex emergencies. Starlink is a potential solution to offer reliable and stable internet connection, helping to bridge the digital divide and providing people with disabilities in humanitarian settings with the same access to information and resources as people in more connected areas.

While there are several conceivable benefits to equipping persons with disabilities with various technologies in humanitarian settings, there are also significant barriers that we would be remiss not to address. Given that most complex emergencies occur in developing countries, the cost of technology and the infrastructure it requires will likely hinder its availability and use. The cost of technology may be unattainable as State funds are often used to address direct and urgent needs rather than invest in something that seems abstract, like technology. Regarding infrastructures, limited internet connectivity and unreliable electricity supply make it difficult to regularly use technology in humanitarian contexts.

There are also barriers related to adoption, sustainability, and overlapping identities of gender, disability, and displacement. Specifically, in many developing countries, women have less access to mobile phones and the Internet (Hunt, 2022), rendering much of the technological solutions above useless. Those with access to available technologies may lack awareness and/or training about using them effectively. As demonstrated throughout this study, women and girls with disabilities in humanitarian settings experience unique circumstances and situations that place them in, at times, extremely vulnerable positions. Therefore, any data collected and managed by the technology used in complex emergencies must remain secure and private.

5.2 Limitations

As with any research, it is important to acknowledge the study's limitations. Several factors for this project proved particularly relevant, including time constraints, accessibility issues, funding limitations, and Western-centric assumptions. Regarding time, the research window was defined by a specific timeframe, which unfortunately meant that some interviews could not be conducted. Despite interest in speaking with potential participants, reliance on snowball sampling and third-party communication across different time zones led to delays and ultimately surpassed the deadline.

Regardless of the project's best efforts to ensure accessibility, two distinct issues emerged that impacted the study's ability to reach and engage its desired participants. The first set of challenges arose from Qualtrics, the online questionnaire tool used in the study, which had few options for customizing how information was presented or accommodating different communication methods of participants. This is an important challenge to consider in general, but especially when prioritizing the full engagement of persons with disabilities. The second set of challenges involved the anticipated engagement with OPDs. It can be assumed that engagement with OPDs was limited due to over-surveying and a lack of trust-building opportunities. Given that OPDs are likely the first line of contact for survey requests, coupled with the timing of the UNDRR's 2023 Survey on Persons with Disabilities and Disasters, it is understandable that OPDs would not prioritize a questionnaire coming from a researcher whom they have no prior relationship.

Funding proved to be a significant limitation, as this project was executed without a budget. The lack of funding resulted in the inability to cover costs associated with sign-language interpreters, translation services, or traveling to conduct field observations. Additionally, I designed this study with incorrect assumptions as a Western researcher. Specifically, I assumed all participants used similar communication methods, access to steady Wi-Fi, and video conferencing platforms like Zoom.

5.3 Final Thoughts

In conclusion, *Gender and Disability: An Exploration of Reflective Practice for Protection and Access Amid Complex Emergencies* successfully took stock of the conditions that enable DPOs to effectively protect and provide access to women and girls with disabilities amid complex emergencies and deepened understanding of the complexity of the disability experience, especially in humanitarian settings. Through comprehensive analyses of the qualitative data collected and extensive research, the study found that women and girls with disabilities encounter unique experiences within humanitarian contexts, and the normative conditions enabling DPOs to effectively protect and provide access to women and girls with disabilities amid complex emergencies include an intersectional approach, rights-based framework, universal design, meaningful engagement, and capacity development.

This study has made notable contributions to the fields of disability, gender, and complex emergencies. It modeled disability inclusive practices throughout the research design, advanced qualitative inquiry in disability studies, brought to life the gender and disability nexus though a composite narrative, and presented a model of normative conditions to increase DPOs effectiveness in protecting and providing access to women and girls with disabilities amid complex emergencies. Such findings and contributions demonstrate the importance and relevance of qualitative research and the intersection of gender and disability, especially in humanitarian contexts, and provides valuable insights for practitioners, policymakers, and researchers.

Although the study opens avenues for further exploration and investigation, it is essential to acknowledge time constraints, sample size, funding, and Western-centric assumptions as limitations. Recommendations for future research endeavors are not limited to including additional time and funding lines to account for disability-related accommodations, longitudinal studies of interventions, field research, and further emphasis on the use of technology to remove barriers. Overall, this study provides a foundation for advancing disability inclusive research and underscores the critical role of qualitative research in understanding the lives of persons with multiple intersecting identities.

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Appendix A: Research Protocol

Gender + Disability: Protections and Access Amid Complex Emergencies

A Questionnaire of Specialists and Practitioners

Research Protocol

Synopsis

Gender + Disability: Protections and Access Amid Complex Emergencies is a research project to explore under what conditions, and in what ways, do disabled-persons organizations effectively protect and provide access to women and girls with disabilities in humanitarian settings through an online questionnaire and targeted semi-structured interviews with leading specialists and practitioners.

As the world's population ages and more people acquire disabilities from diseases, natural disasters, and armed conflict, it is critical to deepen understanding of how the needs of disabled people are met in the context of complex emergencies and beyond. This is particularly critical for women and girls with disabilities, facing compounding inequalities of gender and disability. Additionally, Gender and Disability crosscuts several of the United Nations' sustainable development goals (SDGs), such as Goal 10: Reduced Inequalities and Goal 5: Gender Equality and falls directly at the intersection of the United Nations Office for the Coordination of Humanitarian Affairs policy and studies series "Leave No One Behind: Humanitarian Effectiveness in the Age of the Sustainable Development Goals".

This project engages specialists and practitioners advocating for and/or providing services to women and girls with disabilities in humanitarian settings to explore a central question: **Under what conditions, and in what ways, do disabled persons' organizations effectively protect and provide access to women and girls with disabilities amid complex emergencies?** The project will yield a scholarly journal article and a composite narrative that brings to life the disabled experience in humanitarian settings to be used alongside future studies, guidance notes, and policy recommendations.

The project is conducted by Korbel MA student Lindsey Mandolini. The faculty sponsor for this project is Korbel Professor Timothy D. Sisk.

This Project's Contribution

People with disabilities are two to four times more likely to be injured or die in disasters due to inadequate community-wide planning and access to emergency and disaster assistance (UN Office for Disaster Risk Reduction, 2013). When persons with disabilities flee their homes, they are immediately exposed to disproportionate risks and often receive insufficient aid. The United Nations Human Rights Council (UNHRC) indicates that while en route to the destination country, refugees with disabilities are more susceptible to violence, exploitation, discrimination, and abuse. These vulnerabilities persist at refugee camps where physical, societal, and attitudinal barriers limit access to critical information, health care, accommodations, and rehabilitation services. Moreover, disability-led organizations do not have equitable access to traditional disaster relief channels and often carry the burden of mobilizing resources and filling the gaps of inadequate social safety nets. As of 2019, only 2% of the global human rights and international development funding goes to people with disabilities.[26]

Despite overlapping legal frameworks and policies like the UN Convention on the Rights for Persons with Disabilities, the Sendai Framework for Disaster Risk Reduction, and the Charter on Inclusion of Persons with Disabilities, there has been slow progress in addressing an urgent need. To date, most research addressing disability and complex emergencies has focused on the disproportionate impact that complex emergencies have on persons with disabilities. This body of literature has been critical in developing arguments that shaped the frameworks and policies mentioned above, as well as guidance notes produced by organizations like the WHO, UNHCR, and World Bank. Little research, however, documents the experiences of people with disabilities (Stough & Kelman, 2015). Additionally, the existing literature consists of statistical surveys, responses collected on undifferentiated groups of people with disabilities, or is authored by people without disabilities.

There are substantial gaps in the literature of inclusive qualitative research, resulting in data invisibility, where the people and stories you don't get to hear or see, don't exist (Watharow & Wayland, 2022). Research in the field of disability has typically been done on individuals with disabilities, rather than with them, disempowering this already vulnerable population and taking away their voice (Coons & Watson, 2013). Qualitative research can be a valuable window through which to view the lived experiences of individuals with disabilities in ways that other methods of research do not capture. It can effectively elucidate the experiences of individuals with disabilities in all their complexities and help form policy solutions that address the intricacies of their reality.

The principal aim of this project is to provide a composite narrative that brings to life the disabled experience in humanitarian settings to be used alongside future studies, guidance notes, and policy recommendations. This method allows researchers to use data from several individual interviews to present complex, situated accounts from individuals in a holistic way that represents the overall findings of the research, while preserving

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[26] https://humanrightsfunding.org/populations/disabilities/#issue-focus-panel

confidentiality. The benefit of this approach is that it uses academic methods to build understanding in ways accessible to non-academics.

Methods

The research explores the lived experiences of women and girls with disabilities amid complex emergencies and the conditions that disabled-person organizations effectively protect and provide access to women and girls in humanitarian settings.

- ✓ All participant recruitment and interviews will be conducted in compliance with a University of Denver Institutional Review Board (IRB)-approved protocol to ensure participant consent and confidentiality.
- ✓ An online 20+-minute questionnaire will be posted on Qualtrics to allow for broad participation; invitations to complete the online questionnaire will be distributed broadly across international networks of disabled persons' organizations; recruitment will occur through email and social media channels. The online questionnaire will be available over four weeks (March 6 – March 31). The project team hopes to garner ~30 respondents to the online questionnaire.
- ✓ Based on cluster sampling, the project team will individually recruit up to 25 practitioners (N=25) to interview using a semi-structured thematic framework; the interviews will be conducted virtually (over Zoom) by the principal investigator and recorded for transcription purposes.
- ✓ The questionnaire results will be analyzed, and results will be compiled into a composite narrative and reported in a working paper slated for publication by the end of June 2023 and will be readied for subsequent submission to the Committee on the Rights of Persons with Disabilities.
- ✓ There are no direct or immediate benefits to participants.
- ✓ The project will not interview beneficiaries of disabled persons' organizations in humanitarian settings.

Methods: Online Questionnaire

The project will use existing practitioner networks on social media and in online bulletin boards to recruit participants to complete an online questionnaire of specialists and practitioners working with women and girls with disabilities in humanitarian settings. A list of individuals is also compiled from publicly available online contact information within five major types of organizations: international disability networks, disabled-person organizations; international development assistance providers, or the aid agencies of donor governments; specialists in international organizations, particularly the United Nations specialized agencies (e.g., UNICEF, IOM); the private sector; and specialists in academia typically found in international studies, disability studies, or gender studies.

For of the online questionnaire:

- ✓ A screen will be used through which participants will self-identify as a "specialist or practitioner" with experience working with women and girls with disabilities in humanitarian settings.
- ✓ Consent (attached) will be obtained through online signature with implied consent through the questionnaire.
- ✓ The questionnaire does not request any personal or sensitive information.
- ✓ Given that practitioners may be disabled themselves, and could find some questions triggering, the informed consent script highlights that participants are free to stop at any time, may skip questions if they don't want to answer them, or may choose not to return the questionnaire.
- ✓ Appropriate language is included in the consent form for online research, and Appendix N is submitted with this protocol.

Methods: Virtual Interviews

The project team will identify from the four "clusters" (NGOs, donors, international organizations, private sector, and academia). The project requests authorization for up to 25 interviews, although we anticipate that 10-15 interviews will occur.

For the virtual interviews:

- ✓ Participants will be cluster sampled and identified from publicly available information from each of the five types of organizations.
- ✓ Recruitment will occur via an email from the principal investigator; recruitment script attached. We will use snowball sampling in asking participants for suggestions of additional specialists to interview, especially to "fill in" certain clusters (e.g., international organizations, development donors) where publicly available contact information is often not provided.
- ✓ Participants will be sent an informed consent document in advance and will be asked in the interview, prior to its commencement, that the informed consent document has been received, reviewed, and approved.
- ✓ The virtual interviews will be recorded, and the consent document contains template information that identifies risks and describes data security procedures. We will use Zoom for the videoconferencing software.
- ✓ Recorded interviews will be saved to a password-protected device, files uploaded to a DU server (Zoom), and files then deleted from the device.
- ✓ We foresee no significant risk to participants; the consent form acknowledges some potential personal risk regarding questions relating to disabled experiences in humanitarian settings.

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Appendix B: Questionnaire Instrument

Gender + Disability: Protections and Access Amid Complex Emergencies

A Survey of Specialists and Practitioners

Questionnaire[27]

Before beginning, click below to download and read our IRB-approved informed consent form.

[*Consent Form Hyperlink*]

You are being asked to participate in a research study. To read more about the project research methods click the link below to download a project description. If you have any further questions, please contact the principal investigator or faculty sponsor:

> **Principal Investigator:** Lindsey Mandolini, MA, Korbel School | Lindsey.Mandolini@du.edu
> **Faculty Sponsor:** Timothy D. Sisk, Ph.D, Professor, Korbel School | Timothy.Sisk@du.edu

[*Consent Form Hyperlink*]

Your participation in this research study is voluntary. You may choose to insert your contact information below or skip this question if you would like to remain anonymous. Your information will not be shared with anyone else, and we will not contact you unless you indicate you are interested in participating in a subsequent interview or receiving the project report upon completion. Your responses in this survey will be used in general terms for the distribution of our survey sample.

Name (optional):
Title, Organization (optional):

Thank you for the above information. The next set of questions are open ended, and we appreciate as much detail as you can provide. We are particularly interested in your understanding and lessons learned in your work on this subject. We thank you in advance.

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[27] This questionnaire will be used for the Qualtrics survey and for the virtual interviews.

1. How did you **become involved** in advocating for and/or providing services to women and girls with disabilities in humanitarian settings? How does this inform your understanding of the efficacy of providing protections and access to services to women and girls with disabilities in humanitarian settings?
2. What is an **anecdote or sample experience** you can provide that exemplifies the lived experience of women and girls amid complex emergencies? This need not be a real person, but perhaps a stylized version of those you have encountered.
3. What risks or factors **contribute to vulnerability** in humanitarian settings? (Age, location, type of disability, etc.) What circumstances created that?
4. Describe how is **disability viewed** in the region where you work. What are the knowledge, attitudes and perceptions of humanitarian actors and/or local communities with regard to persons with disabilities?
5. What are specific **risks or barriers** that persons with disabilities encounter when accessing assistance in complex emergencies? What are **enabling factors for access to assistance**?
6. What is the **primary concern** when women and girls with disabilities meet with you? (Safety, security, shelter, health, employment, etc.) What tends to be the most common **long-term concern**?
7. To what extent do individuals **understand their rights and access** to accommodations? How often are their rights protected and accommodations met?
8. What personal and family **resilience factors** do women and girls with disabilities rely upon in coping with complex-emergency conditions?
9. When thinking about the various levels of displacement, from evacuation to (short term displacement- shelters, long term displacement - camps) to reintegration. What tends to be the **most challenging stage** for your beneficiaries Why?
10. What factors contribute to your client's **rehabilitation**, sense of autonomy and empowerment? What resources and/or approaches were most successful?
11. How is **social integration** best advanced for women and girls with disabilities who have been displaced? In what ways can disabled persons' organizations assist women and girls with disabilities in reaching social re-integration?
12. What are the most effective ways disabled persons' organizations can assess and assure **cultural and contextual appropriateness** in their response advocating for and/or providing services to women and girls with disabilities? What were least effective?
12. In your view, to what extent has **international and/or national policy** related to humanitarian assistance and disability impacted the people you work with on an organizational or individual level?
13. There is a growing trend to equip and empower disabled persons' organizations to respond to complex emergencies. What additional resources, in what forms, would **enable your organizations** work to be most effective?
14. To what extent do you work with international agencies? What impact do they have on your clients or work? What are the **priority actions** that humanitarian actors should take to better include persons with disabilities?

15. What do you see as the **main gaps** in terms of inclusive humanitarian response? In what ways can the response capacities of local organizations be strengthened? What specific capacity-development approaches are most effective?
16. What is the most innovative or promising **new developments in inclusive humanitarian response** in recent years? Alternately, what new approaches and methods hold the most promise for further investment in protecting the rights and improving access to services
17. What are the most important **lessons learned for reflective practice** in this area of practice that you would share with other specialists and practitioners working with women and girls with disabilities in humanitarian settings?

Is there anything important we may have missed? Please share your final thoughts.

The project team is also collecting additional resource material for the project, and **we invite you to upload any publicly distributable information that you are allowed to share, such as project documents, written work, blog posts, or presentations**. We ask that confidential information on projects or programs, or those that list project beneficiaries, not be shared and in any event the team will only reference in any reports or published material authorized publicly available information.

[*Drop files or click here to upload*]

Appendix C: Informed Consent

Gender + Disability: Protections and Access Amid Complex Emergencies

A Survey of Specialists and Practitioners

Informed Consent for Online Surveys

You are invited to participate in a research study of Gender + Disability: Protections and Access Amid Complex Emergencies to explore under what conditions, and in what ways, do disabled persons organizations effectively protect and provide access to women and girls with disabilities in humanitarian settings. The project will yield a scholarly journal article and a composite narrative that brings to life the disabled experience in humanitarian settings to be use alongside future studies, guidance notes, and policy recommendations. You were selected as a possible participant in this study because you are a practitioner working with women and girls with disabilities in a humanitarian setting.

If you decide to participate, please understand your **participation is voluntary** and you have the **right to withdraw and discontinue participation at any time without penalty or loss of benefits to which you are otherwise entitled**. **The alternative is not to participate**. If you decide to participate, complete the following survey. Your completion of this survey indicates your consent to participate in this research study. The survey is designed to elicit your understanding and knowledge on the lessons learned of the protections and access to services by women and girls with disabilities in humanitarian settings.

The survey approximately 20 minutes to complete, however participants have the opportunity to provide further detail to the open-ended questions. You will be asked to answer questions about the risks, barriers, and enabling factors that women and girls with disabilities experience amid complex emergencies, as well as the knowledge, attitudes, and perceptions of humanitarian actors and local communities with regard to women and girls with disabilities.

There are no direct benefits to participation in this study. A broader benefit is sought through the research's potential for contribution to deepen understanding of the lived experiences of women and girls with disabilities amid complex emergencies and effective design in protecting and providing access in humanitarian settings. The results will be widely distributed in policy and practitioner networks.

Should you experience any discomfort or inconvenience because of discussing the experiences of women and girls with disabilities amid complex emergencies, you are free to stop at any time; you may also skip questions if you don't want to answer them or may choose not to return the survey. Any discomfort or inconvenience are not expected to be any greater that anything you encounter in everyday life. Your decision whether or not to participate will not affect your future relationship with the organization you are connected to, nor the University of Denver.

Data will be collected using the Internet; no guarantees can be made regarding the interception of data sent via the Internet by any third party. Confidentiality will be maintained to the degree permitted by the technology used. The link between your identifiers and the research data will be destroyed after the records retention period required by state and/or federal law. No other organizations or agencies have access to the data, nor will the data be released to research subjects.

Before you begin, please note that the data you provide may be collected and used by Qualtrics per its privacy agreement. Please be mindful to respond in private and through a secured Internet connection for your privacy. Your confidentiality will be maintained to the degree permitted by the technology used. Specifically, no guarantees can be made regarding the interception of data sent via the Internet by any third parties. Your name will not be used in any report. Identifiable research data will be encrypted and password protected.

Please feel free to ask questions regarding this study. You may contact me if you have additional questions at:

Lindsey Mandolini
Josef Korbel School of International Studies
Email: Lindsey.Mandolini@du.edu
Phone: +1 616 299-4840

For questions, concerns, or complaints about the study you may contact:

Professor Timothy D. Sisk
Josef Korbel School of International Studies
Email: timothy.sisk@du.edu
Phone: +1 303 871-2998

If you are not satisfied with how this study is being conducted, or if you have any concerns, complaints, or general questions about the research or your rights as a participant, please contact the University of Denver (DU) Institutional Review Board to speak to someone independent of the research team at (303) 871-2121, or email at IRBAdmin@du.edu.

Please take all the time you need to read through this document and decide whether you would like to participate in this research study.

Thank you for your time.
Sincerely,

Lindsey Mandolini, MA, Korbel School
Timothy D. Sisk, Ph.D., Professor, Korbel School

By clicking the link below, I confirm that I have read this form and decided that I will participate in the project described above. Its general purposes, the particulars of involvement, and possible risks and inconveniences have been explained to my satisfaction. I understand that I can discontinue participation at any time. My consent also indicates that I am at least 18 years of age. [Please feel free to print a copy of this consent form.]

☐ I agree to participate (link to survey) ☐ I decline (link to close webpage)