TOWARDS DISABILITY TRANSFORMATIVE EARLY WARNING SYSTEMS: Barriers, challenges and opportunities

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June 2021
ACKNOWLEDGEMENTS:

The authors are grateful for the support of Practical Action throughout this project, particularly Alison Sneddon and Mirianna Budimir, who’s guidance and expertise was instrumental to the report’s outcome. We would also like to extend our thanks to our coaches, Dr Alessandra Radicati (LSE) and Dr Naomi Pendle (LSE) for their continuous advice.

Special gratitude is extended to Pratima Gurung and Edmos Mthethwa for reviewing earlier drafts of this work and for providing invaluable comments and insights.

Lastly, we give our biggest thanks to the twelve interviewees for sharing their time and insights with us.

ETHICS:

The research conducted in this project was approved by the LSE Ethics Committee and was carried out in accordance with the Code of Research Conduct. A consent form detailing the purpose of the research and the interview procedures was signed by each of the participants prior to the interviews. All effort has been made to anonymise participants’ identities and maintain confidentiality. Interview recordings and transcripts have been managed and stored securely, in compliance with both the LSE’s Research Ethics policies and Data Management Practice.

DISCLAIMER:

The views expressed in this report are those of the authors and do not necessarily reflect the views of the London School of Economics and Political Science or Practical Action.

NOTE ON TERMINOLOGY:

This paper refers to “persons with disabilities” (PWDs) throughout, following the terminology used by the International Disability Alliance, and the United Nations. The authors recognise different individuals, organisations and groups have different preferences for terminology, and prioritises following each individual’s own language when referring to individuals. Just as the terminology surrounding PWD is contested, so too is the terminology surrounding organizations who represent them. This paper refers to these organisations as DPOs. Other terminology used include organisations of persons with disabilities.

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# TABLE OF CONTENTS

<table>
<thead>
<tr>
<th>Section</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>EXECUTIVE SUMMARY</td>
<td>4</td>
</tr>
<tr>
<td>GLOSSARY</td>
<td>7</td>
</tr>
<tr>
<td>ACRONYMS AND ABBREVIATIONS</td>
<td>9</td>
</tr>
<tr>
<td>INTRODUCTION</td>
<td>10</td>
</tr>
<tr>
<td>PREFACE: DEFINING DISABILITY</td>
<td>12</td>
</tr>
<tr>
<td><strong>PART 1: THEMATIC LITERATURE REVIEW</strong></td>
<td>16</td>
</tr>
<tr>
<td>VULNERABILITY</td>
<td>17</td>
</tr>
<tr>
<td>PARTICIPATION</td>
<td>18</td>
</tr>
<tr>
<td>POWER AND DECISION-MAKING</td>
<td>19</td>
</tr>
<tr>
<td>COMMUNICATION AND DISSEMINATION</td>
<td>20</td>
</tr>
<tr>
<td>RESPONSE</td>
<td>23</td>
</tr>
<tr>
<td><strong>PART 2: KEY INTERVIEW FINDINGS</strong></td>
<td>25</td>
</tr>
<tr>
<td>POLICY VS. PRACTICE</td>
<td>26</td>
</tr>
<tr>
<td>ABLEISM</td>
<td>26</td>
</tr>
<tr>
<td>DATA AND DEFINITIONS</td>
<td>27</td>
</tr>
<tr>
<td>INTERSECTIONALITY AND INDIVIDUALISM</td>
<td>28</td>
</tr>
<tr>
<td><strong>PART 3: CASE STUDIES</strong></td>
<td>29</td>
</tr>
<tr>
<td>ZIMBABWE</td>
<td>30</td>
</tr>
<tr>
<td>NEPAL</td>
<td>32</td>
</tr>
<tr>
<td><strong>PART 4: MOVING FORWARD</strong></td>
<td>36</td>
</tr>
<tr>
<td>TWIN-TRACK APPROACH</td>
<td>37</td>
</tr>
<tr>
<td>UNIVERSAL DESIGN AND DISABILITY TRANSFORMATIVE EARLY WARNING DISSEMINATION</td>
<td>39</td>
</tr>
<tr>
<td>BEYOND DEFINITIONS</td>
<td>40</td>
</tr>
<tr>
<td>MEANINGFUL PARTICIPATION</td>
<td>41</td>
</tr>
<tr>
<td><strong>CONCLUDING REMARKS AND RECOMMENDATIONS</strong></td>
<td>43</td>
</tr>
<tr>
<td><strong>BIBLIOGRAPHY</strong></td>
<td>47</td>
</tr>
<tr>
<td><strong>APPENDIX: REFLEXIVITY AND ADDITIONAL CONCERNS</strong></td>
<td>53</td>
</tr>
</tbody>
</table>
EXECUTIVE SUMMARY

DISABILITY, EARLY WARNING SYSTEMS AND DISASTER RISK REDUCTION

Early warning systems (EWS) and disaster risk reduction (DRR) programming remain some of the most effective ways to save lives during a disaster. The earlier a person is warned of a hazard and the more prepared they are, the more time they have to make critical life-saving decisions. This report finds, however, that most EWS and DRR programmes are unable to account for the heterogeneous needs of affected communities, thus, effective EWS and DRR practices should focus on the context specific needs of communities and the individuals within them to ensure that no one is left behind.

Despite the fact that there are an estimated 600 million persons with disabilities in the world, very little has been done to create inclusive and comprehensive EWS which meet the needs of individuals with physical or cognitive impairments. This report highlights how systemic barriers and challenges faced by persons with disabilities (PWD), not only exclude them from decision-making in DRR practices, but also from functions of
everyday life. While it is imperative to address the lack of research into effective and inclusive EWS, it is also key for organisations to address the systemic barriers that lead to exclusion of PWD from decisions regarding their own lives. This report finds few examples of this being put into practice, however. It is for this reason that the phrase “nothing about us, without us” is central to this report as it aims to understand:

1. The barriers, challenges and opportunities people with disabilities experience regarding early warning systems and disaster risk reduction planning and programming, and;

2. What practitioner organisations have done to reduce the impact that disability has on people’s experience of disaster, and to examine what they have learned and could improve in the future.

REPORT STRUCTURE

The report begins by attempting to understand the complexity of defining disability, crucial in overcoming barriers related to meaningful participation of PWD, such as data collection. It attempts to capture the heterogeneity of disability in order to appreciate the diverse range of needs and capabilities related to disability. Consequently, the report urges readers to think beyond definitions, and to focus instead on a rights-based approach that applies an understanding of universal design to all EWS and DRR programs rooted in a social model of disability.

This is followed by a thematic literature review to understand the positionality of PWD in relation to EWS and DRR. The five key themes addressed are: 1) Vulnerability; 2) Participation; 3) Power and Decision-Making; 4) Dissemination; and 5) Response. While it is clear that research has been growing on the topic of disability and disasters over the past decade, the theoretical policy recommendations made have yet to be put to practice. The report finds that historically identified barriers and challenges for PWD persist today, and that practitioner organisations are not doing enough to reduce the impact of disability on experience of disaster.

The literature review findings are supported by twelve in-depth, semi-structured interviews conducted with prominent disability scholars and activists from the UK, USA, Nepal and Zimbabwe. These interviews provided a greater understanding of the evolution of disability and disaster studies and the current state of research. Interviewees highlighted both context-specific barriers, challenges and opportunities, as well as experiences of systemic challenges faced by PWD. The key findings of the report emerge within four thematic areas: 1) Policy vs Practice; 2) Ableism; 3) Data and Definitions; and 4) Intersectionality and Individualism. Additionally, the interviews highlighted the need for a twin-track approach to tackle both systemic and context-specific challenges faced by PWD.
The report then applies these findings by focusing on understanding the barriers, challenges and opportunities specific to two case studies: Nepal and Zimbabwe. These countries were selected based on Practical Action’s presence in the countries, working history, and available data. Literature reviews were conducted for each to determine the current state of disability policy and practice in general and in relation to disasters. Interviews were held with individuals from those countries, who have extensive experience working in the field. The structure and findings of the case studies are primarily driven by the interviews, which yield rich, contextual insights of specific challenges, but also examples of practical work being done to include PWD in DRR and EWS planning and programming.

The final section of the report describes the path forward for disability transformative EWS and DRR practices, which are: 1) Utilising a twin-track approach; 2) Adopting universal design; 3) Moving beyond definitions of disability; and 4) Ensuring meaningful participation of PWD. These pathways attempt to address the systemic exclusion of PWD in everyday life, as well as in EWS and DRR planning and implementation. Put simply by one of the interviewees: “disabled people are not the problem” (Interviewee 7). By tackling systemic oppression from a societal and organisational level, by adopting universal design as a tool to ensure equity for all people, and by putting into practice the phrase “nothing about us, without us”, practitioner organisations can work towards disability transformative EWS and DRR practices.

**RECOMMENDATIONS**

The six key broad recommendations identified in this report for the development of disability transformative DRR policies and EWS are:

1. Challenge and address the systemic and structural ableism within societies, governments and NGOs.
2. Implement policies more effectively and with greater accountability to the people for whom they are designed to support.
3. Adopt a twin-track approach to disability which combines a universal strategy with targeted responses to peoples’ specific functional needs.
4. Implement Universal Design to ensure all facets of an EWS are accessible to everybody in society irrespective of functional needs.
5. Reconsider how disability is defined, who is defining it and what purpose it serves.
6. Ensure that the participation of PWD is meaningful and effectively empowers them to make decisions which honour the phrase “nothing about us, without us.”
<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
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<tbody>
<tr>
<td>Ableist</td>
<td>Discriminatory against people with disabilities</td>
</tr>
<tr>
<td>Accessibility</td>
<td>Accessibility describes the degree to which an environment, service, or product allows access by as many people as possible, in particular people with disabilities. (World Bank)</td>
</tr>
<tr>
<td>Capacity</td>
<td>An ICF construct that indicates the highest probable level of functioning that a person may achieve, measured in a uniform or standard environment: reflects the environmentally adjusted ability of the individual. (ICF)</td>
</tr>
<tr>
<td>Disaster</td>
<td>A serious disruption of the functioning of a community or a society at any scale due to hazardous events interacting with conditions of exposure, vulnerability, and capacity, leading to one or more of the following: human, material, economic, and environmental losses and impacts (UNISDR)</td>
</tr>
<tr>
<td>Disability inclusion</td>
<td>Understanding the relationship between the way people function and how they participate in society, and making sure everybody has the same opportunities to participate in every aspect of life to the best of their abilities and desires (CDC)</td>
</tr>
<tr>
<td>Early warning</td>
<td>Information communicated to stakeholders to advise them of the likelihood of a disaster occurring within a given timeframe</td>
</tr>
<tr>
<td>Early warning system</td>
<td>An integrated system of hazard monitoring, forecasting and prediction, disaster risk assessment, communication, and preparedness activities, systems, and processes that enables individuals, communities, governments, businesses, and others to take timely action to reduce disaster risks in advance of hazardous events (UNISDR)</td>
</tr>
<tr>
<td>Hazard</td>
<td>A process, phenomenon, or human activity that may cause loss of life, injury, or other health impacts, property damage, social and economic disruption, or environmental degradation (UNISDR)</td>
</tr>
<tr>
<td>Impairment</td>
<td>Any temporary or permanent loss or abnormality of a body structure or function, whether physiological or psychological. An impairment is a disturbance affecting functions that are essentially mental (memory, consciousness) or sensory, internal organs (heart, kidney), the head, the trunk or the limbs (WHO)</td>
</tr>
<tr>
<td>Intersectionality</td>
<td>A framework for understanding how individuals’ identities and social positions are shaped by the intersection of multiple factors at the same time. Such factors include but are not limited to; disability, gender identity, class, caste, faith and sexuality (UNDP)</td>
</tr>
<tr>
<td>Defined Term</td>
<td>Definition</td>
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<tr>
<td>Preparedness</td>
<td>The knowledge and capacities developed by governments, response and recovery organisations, communities, and individuals to effectively anticipate, respond to, and recover from the impacts of likely, imminent, or current disasters (UNISDR)</td>
</tr>
<tr>
<td>Resilience</td>
<td>The ability of a system, community, or society exposed to hazards to resist, absorb, accommodate, adapt to, transform, and recover from the effects of a hazard in a timely and efficient manner, including through the preservation and restoration of its essential basic structures and functions through risk management (UNISDR)</td>
</tr>
<tr>
<td>Universal design</td>
<td>The design of products, environments, programmes and services to be usable by all people, to the greatest extent possible, without the need for adaptation or specialised design (CRPD)</td>
</tr>
<tr>
<td>Vulnerability</td>
<td>The conditions 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 (UNISDR)</td>
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<tr>
<td>Acronym</td>
<td>Description</td>
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<td>---------</td>
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<tr>
<td>CERT</td>
<td>Community Emergency Response Team</td>
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<td>CPRD</td>
<td>United Nations Convention on the Rights of Persons with Disabilities</td>
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<td>CBP</td>
<td>Community Based Practices</td>
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<td>DRR</td>
<td>Disaster Risk Reduction</td>
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<td>DPO</td>
<td>Disabled People’s Organisation</td>
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<td>DiDRR</td>
<td>Disability-inclusive Disaster Risk Reduction</td>
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<td>DAISY</td>
<td>Digital Accessible Information System</td>
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<td>DEWN</td>
<td>Disaster Emergency Warning Network</td>
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<td>DEWS</td>
<td>Drought Early Warning System</td>
</tr>
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<td>EWDN</td>
<td>Early Warning Dissemination Network</td>
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<tr>
<td>EWS</td>
<td>Early Warning Systems</td>
</tr>
<tr>
<td>GFDRR</td>
<td>Global Facility for Disaster Reduction and Recovery</td>
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<td>IFRC</td>
<td>International Federation of Red Cross and Red Crescent Societies</td>
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<tr>
<td>ICF</td>
<td>International Classification of Functioning, Disability and Health</td>
</tr>
<tr>
<td>MDS</td>
<td>The Model Disability Survey</td>
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<tr>
<td>MHEWS</td>
<td>Multi Hazard Early Warning System</td>
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<tr>
<td>NCD</td>
<td>U.S. National Council on Disability</td>
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<tr>
<td>NGO</td>
<td>Non-Governmental Organisation</td>
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<td>PWD</td>
<td>People/Persons with Disabilities</td>
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<tr>
<td>SFDRR</td>
<td>Sendai Framework for Disaster Risk Reduction</td>
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<tr>
<td>UD</td>
<td>Universal Design</td>
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<tr>
<td>UNISDR</td>
<td>United Nations International Strategy for Disaster Reduction</td>
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<td>UNDRR</td>
<td>United Nations Office for Disaster Risk Reduction</td>
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<td>WG-SS</td>
<td>The Washington Group Short Set on Functioning</td>
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<td>WHO</td>
<td>World Health Organisation</td>
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<td>WCDRR</td>
<td>United Nations World Conference on Disaster Risk Reduction</td>
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INTRODUCTION

There are more than 600 million people living with disabilities in the world, with 80% living in Lower Income Countries. PWD are disproportionately vulnerable to the effects of disasters, not only because of their impairments, but primarily because of systemic failures to include them and their needs when planning and designing EWS. Put simply, ‘disaster preparedness and emergency response systems are typically designed for people without disabilities, where escape or rescue involves running, driving, seeing, hearing, and quickly responding to instructions, alerts, and evacuative announcements’ (Sullivan & Häkkinen, 2011, p. 229). In fact, only 20% of PWD report being able to evacuate immediately and without difficulty in the case of a sudden onset disaster (UNDRR, 2013). Most EWS are designed by and for nondisabled people, and it is for this reason that PWD are more likely to be killed during or after a disaster than anyone else. Despite this, the necessary measures required to decrease the vulnerability of PWD have yet to be taken, or fully understood. Though there are a number of governments as well as local and international NGOs doing important work in this field, there is yet to be a singular effort to collate, synthesise and understand the existing research on the topic, a gap this report attempts to fill. Moreover, Lower Income Countries are particularly overlooked in the literature, and significant gaps exist regarding how PWD in these countries can be protected. In order to address these gaps directly, this report employs two case studies: Nepal and Zimbabwe. Each examines the context-specific challenges faced by PWD in accessing disaster protection and ways to move forward. Evidently more must be done to effectively understand and serve the needs of those at risk from hazards. It is upon this premise that the project is motivated; it asks the following research questions:

- What are the barriers, challenges and opportunities for people with disabilities related to EWS/DRR?

- What have practitioner organisations specifically done to reduce the impacts that disabilities have on people’s experience of disasters? Are there any existing strategies, approaches, or projects that have worked to help those with disabilities overcome these challenges?

The report finds the barriers and challenges for PWD in relation to EWS and DRR to be significant. A critical lack of participation in planning and decision making exacerbates the vulnerability faced by PWD in disaster settings, much of which is the result of an ableism endemic to societies, governments and NGOs. Both the literature review and the interviews failed to identify significant examples of practitioner organisations successfully mitigating the effects of disability on the experience of disasters. Best practice remains theoretical and is yet to be demonstrated meaningfully.
METHODOLOGY

To answer these questions, a qualitative multi-method research design was employed, consisting of a literature review and key-informant interviews. The literature review provides an examination of grey and academic literature. A number of electronic databases were used to retrieve articles, and were categorised by their focus: vulnerability, participation, power and decision-making, dissemination, or response. Though there exists a relative lack of literature which specifically addresses disability in DRR and EWS, this gap is filled with insights from twelve in-depth, semi-structured interviews. Participants were identified through their reputation in the field and through snowball sampling, among them are prominent disability scholars and activists from the UK, USA, Nepal and Zimbabwe. To the benefit of this project, three of the participants themselves have disabilities and were able to provide insights upon which most of our findings rest, though they will not be identified or referred to as PWD in this report in order to protect their anonymity. Interviews were conducted via Zoom from December 2020 to February 2021, and lasted between 25 and 50 minutes. They were transcribed, coded and used to supplement the findings of the literature review and to comprise a large part of the two case studies. Interview recordings and transcripts have been managed and stored securely, in compliance with both the LSE’s Research Ethics policies and Data Management Practice. The sample size means that our findings are not generalisable, and do not represent a consensus either within the countries examined or about disability more generally. They do, however, provide rich, experienced and localised insights that have demonstrated the value and importance of proactively seeking out the perspectives of PWD.

REFLEXIVITY

It is important to recognise that this report has been written by nondisabled authors, and to acknowledge the implications that extend from this privilege. We do not claim to speak for, or on behalf of PWD, and have made every effort to center their voices in this report. PWD must be the authorities of their own experience. We have endeavoured to include PWD at all stages of the project, for example by seeking and prioritising literature written by PWD during the review process, and seeking interviews with PWD. Despite this, PWD are underrepresented in both our interview sample and in the literature. This reflects the structural exclusion of PWD across and within institutions of all kinds. We are aware of, and have accounted for, the inherent power inequalities between researcher and researched, and thus resist any normative interpretations of our research findings. More must be done, and it is hoped that this research can make clear the human cost of continuing to marginalise, sideline and exclude PWD from DRR and EWS research, planning and implementation.
This report is prefaced by a discussion on how disability is defined. Whilst this may seem self-evident, disability must be defined in order to allow disaggregated data collection which can be used to advocate for the rights of, and provide adequate support for PWD. The importance of data is clearly outlined within the guiding principles of the Sendai Framework for Disaster Risk Reduction (SFDRR) and is consistently emphasised within the literature and by the interviewees. Despite this, disability is an “evolving concept” which differs across cultural contexts (UNDP, 2011, p. 16), and ultimately “there isn’t and never will be a single definition of disability” (Grech, 2016, p. 217). The conceptualisation of disability has significant influence over how disability statistics are collected. Thus, it is vital that these conceptualisations are understood (Eide & Loeb, 2016).

There are two key conceptualisations of disability; the medical model and the social model. The medical model focuses upon physical limitations and individual experiences as a result of their impairment(s), thus the problem-and solution-is located within the individual, not societal level (SCOPE, 2020; WHO, 2002). In contrast, the social model shifts the focus towards society. The limitations a person experiences are not the result of their impairment(s), but rather people become disabled through barriers that exist within societies that limit their ability to function (SCOPE, 2020). The social model is emphasised within the Convention on the Rights of Persons with Disabilities (CRPD) and represents a shift away from viewing PWD as in need of assistance towards a recognition of their human rights (Eide & Loeb, 2016). In this context the World Health Organisation (WHO) developed the International Classification of Functioning, Disability and Health (ICF) as an attempt to synthesise both models into one ‘biopsychosocial’ model presented in Figure 1. Within this model, disability is categorised as a dysfunction produced through the interaction between health conditions and contextual factors, an attempt to holistically conceptualise disability. This report utilises the internationally recognised ICF as the most appropriate way to account for the combination of factors which produce disability.

The adoption of a medical, social or ICF ‘biopsychosocial’ model of disability will have a significant impact upon how data on disability is collected. The ICF as the internationally recognised best approach to conceptualising disability is often the
starting point for the collection of data. Yet, the ICF model, whilst an effective theoretical tool for understanding what disability entails, is most effective in a clinical or rehabilitative setting and is not useful as a method of data collection more generally (Eide & Loeb, 2016). Subsequently there have been multiple attempts to build upon the ICF model to produce practical methods of estimating the prevalence of disability in the wider population. The three most prevalent methods are: The Model Disability Survey (MDS); Washington Group Short Set on Functioning (WG-SS) and Medical counting. The key features of each method are highlighted in Figure 2.

- Recognising the ICFs practical limitations the WHO developed the MDS as an attempt to make the ICF more useful for data collection purposes (World Health Organization, 2017). The survey consists of a questionnaire comprising 294 questions and builds a scale of disability from 0-100 on which PWD are then placed (Groce, 2018; World Health Organization, 2017). Whilst this survey provides a comprehensive and nuanced picture of disability, it is complex and requires a certain level of technical capacity and a commitment to further analysis and interpretation (Groce, 2018).

- Medical, often census, based counting conversely builds upon the medical model and thus has a narrower understanding of disability. The main benefit of this approach is that it will provide clear definitions of disability, which can be used to collect data more easily on disability prevalence (Eide & Loeb, 2005). A medical counting of disability, however, will often be “confounded by cultural, contextual and environmental factors” (Eide & Loeb, 2005, p. 17). By focusing solely on the impairments an individual may face, such an approach cannot account for the elements of society which can influence how disability is experienced at an individual level.

- Finally the WG-SS are an attempt to bridge this gap between the comprehensive understanding of disability within the ICF and MDS and the practical benefits of medical counting. The WG-SS consists of six questions about six levels of functioning, and is considered effective for census taking given its brevity, simplicity and broad scope (Washington Group, 2020). Whilst a useful tool in some situations, it is not a panacea and can exclude key sections of disabled populations, particularly the most vulnerable.

<table>
<thead>
<tr>
<th>Method of Disability Data Collection</th>
<th>MDS</th>
<th>Medical Counting</th>
<th>WG-SS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Is disability social or medical?</td>
<td>Both</td>
<td>Medical</td>
<td>Both</td>
</tr>
<tr>
<td>Comprehensive accounting of disability?</td>
<td>Yes</td>
<td>No</td>
<td>No</td>
</tr>
<tr>
<td>Easily applied across contexts?</td>
<td>No</td>
<td>No</td>
<td>Yes</td>
</tr>
</tbody>
</table>

FIGURE 2. KEY FEATURES OF EACH METHOD OF DISABILITY COLLECTION
Whilst the MDS and WG-SS represent the international consensus that the social dimensions of disability influence the medical dimensions of impairment, there remains a gap between the practical realities of defining and collecting data on disability. In many low-income countries disability statistics are often collected through national censuses which typically rely upon impairment based, medical understandings of disability (Eide & Loeb, 2016). This is compounded by limited understandings of disability, prejudice, poor infrastructure and a lack of training, all of which produces persistently low estimates of disability prevalence in many Lower Income Countries (Eide & Loeb, 2016). Ultimately, there is no consensus on how to best capture the complex picture of disability within countries. Not least because individuals may not want to be defined as disabled, or disability may not exist within their understanding of the world or may exist in another form which data collection methods do not capture (Eide & Loeb, 2016). Furthermore “theoretical elements of the social model of disability may fall short of being transformational in certain ‘Global South’ contexts, not least because this model may be hardly known, and because it may face deep problems when faced by poverty contexts” (Eide & Loeb, 2016, p. 276). At present the use of a combination of all three methods can and does produce a patchwork and piecemeal understanding of disability prevalence within countries and often represents an imperfect solution to a multifaceted question. Greater attention however needs to be paid to how disability can be effectively measured in all development contexts. Finding an effective solution to accurately capturing the disability picture within and across countries is vital and is an important first step on the path towards more equitable DRR policy, EWS and society more generally.

As is emphasised throughout this report, there exists a broad spectrum of physical and mental impairments which can have disabling effects on an individual. Subsequently, this section should not be understood as an attempt to provide a universal definition of disability, but rather as an attempt to acknowledge the current approaches to, and complexity of, defining disability. To better conceive the heterogeneity of impairments that fall under the disability category and the implications they have on the experience of disaster, a non-exhaustive list is included below.

- Visual impairments
  - Refers to people who are blind or have partial vision. Impacts include reduced access to text-based and visual EWS (e.g. signage, flags, digital alerts) and decreased mobility due to environmental change (disaster).

- Auditory impairments
  - Refers to the reduced or total loss of hearing in one or both ears. Can render auditory EWS (e.g. sirens, alarms, loudspeakers) ineffective. It limits communicative potential (requires knowledge of sign-language/lip-reading, access to hearing aids or writing equipment) in disaster settings.
• Physical impairments
  o Includes a broad range of impairments which limit/reduce physical functioning, commonly affecting either mobility, dexterity or stamina. Physical impairments may pose additional challenges to evacuation and/or limit capacity to respond to early warnings.

• Psychiatric impairments
  o Includes the broad range of ‘mental illnesses’ that affect the mind and the way a person thinks/feels/acts. Examples include, but are not limited to, depression, bipolar disorder, schizophrenia, anxiety and personality disorders. They are invisible, often misunderstood and in many contexts stigmatised. Dependence on care givers/caring mechanisms becomes pronounced in disaster settings.

• Intellectual, learning or cognitive impairments
  o Reduces capacity to learn tasks, process information, and limits communicative, social and safety skills. Capacity to understand and respond to a broad range of early warnings may be limited without extensive training.
PART 1: THEMATIC LITERATURE REVIEW

SUMMARY OF LITERATURE REVIEW FINDINGS
The amount of academic literature on the barriers and challenges faced by PWD within DRR and when developing effective EWS has grown in the past decade. Despite this, there is still a significant lack of information, especially when compared with other socially marginalised groups. Thus, this literature review attempts to summarise the prevailing research on the barriers and challenges to disability transformative DRR and EWS, whilst acknowledging that it is by no means authoritative and that significant gaps still remain. The key findings of this section are:

- **VULNERABILITY**
  Pre-existing vulnerabilities of PWD caused by existing inequalities are exposed and exacerbated by disasters.

- **PARTICIPATION**
  Participation of PWD in DRR planning and practice remains feeble, despite the growing number of research and policy initiatives, revealing the desperate need for inclusion.

- **POWER AND DECISION-MAKING**
  PWD have historically been void of power and authority. While significant progress was made in SFDRR, implementation and practices are yet to be seen.

- **COMMUNICATION AND DISSEMINATION**
  There is a thorough lack of research on communication and dissemination in EWS, and existing measures are inadequately designed to warn PWD.

- **RESPONSE**
  The challenges that PWD face during the response phase is heavily influenced by the above factors which results in individualisation of responses.
Vulnerability

Vulnerability is highly contextual, complex and vague (Sparf, 2016). Most definitions of vulnerability agree that the impacts of disasters are not random, but influenced by societal factors (Chou et al., 2004). In other words, the vulnerability experienced by an individual or group of people is constructed and “disasters do not create vulnerability or vulnerable groups” but rather reflect pre-existing inequalities within society (Sparf, 2016, p. 245). Vulnerability is comprised of the characteristics of a person or group, their sensitivities or exposures to shocks, and their capacity to anticipate, cope with and recover from the impact of a crisis (Sparf, 2016; Wisner, 2013). PWD are particularly disempowered and disadvantaged as a group and therefore are made more vulnerable (Abbott & Porter, 2013). The relationship between disability and poverty is important in this context, and the relationship is often presented as cyclical (Grech, 2016). “Individuals living in poverty have a higher risk of acquiring diseases and impairments, and PWD usually become poorer because of reduced opportunities, stigma, and costs of care” (Landry et al., 2016, p. 1719). Impoverishment can diminish the capabilities of PWD and exacerbate impairments through persistently inaccessible healthcare (Grech, 2016). The relationship between poverty and disability however is under researched, especially in rural locations, and the voices of PWD living in extreme poverty are notably absent (Grech, 2016). Disasters also have a dual effect on disability, they can both cause impairments and compound those which already exist (Kent & Ellis, 2015; King et al., 2019; Lunga et al., 2019). Whilst research on the specific vulnerability of PWD remains limited, it is clear that through broader societal issues the constructed vulnerability of PWD is exacerbated (Abbott & Porter, 2013; Chou et al., 2004; Osaki & Minowa, 2001; Rahimi, 1993).

WHICH FACTORS INCREASE THE VULNERABILITY OF PWD?

Many of the factors which create vulnerability are present in the lived experiences of PWD (Sparf, 2016). Twigg (2014) quotes the IFRC and outlines three characteristics which increase vulnerability: “proximity/exposure [to hazards], poverty, and exclusion/marginalisation” (p. 469). The experiences of PWD can be characterised by all three. They are typically amongst the poorest in society, something which holds true both in High and Lower Income countries (Priestley & Hemingway, 2007). Moreover, PWD face persistent marginalisation and exclusion consequent of societal stigma, isolation and discrimination (Peek & Stough, 2010). This informs the fact that PWD are more likely to live in places exposed to disasters and in greater concentrations than other groups (Alexander et al., 2012; Chakraborty et al., 2019). Inadequate dissemination methods and inaccessible communication is another factor which negatively impacts the vulnerability of PWD (White, 2014). During a disaster PWD may experience significant losses of interpersonal support or mobility aids, which can be vital for their
effective functioning (King et al., 2019). Infrastructure damage during a disaster can also compound the inaccessibility of the built environment for PWD (Imrie & Thomas, 2008).

Vulnerability is not just experienced at the point of disaster. PWD face heightened exposure ex post and are often the least likely to evacuate (Dash & Gladwin, 2007; Peek & Stough, 2010). In shelters their heterogeneous needs are often overlooked, by communities and local government, which exacerbates their vulnerability beyond the immediate impact of disasters (Tatsuki, 2012). Shelters are built with almost no regard for the needs of PWD, and the inaccessible geographies of the everyday are transplanted into the shelter space (King et al., 2019). Within shelters, PWD face an increased risk of sexual assault or violence, though the causal reasons for this are poorly researched (King et al., 2019). Consequently, shelters may ultimately not be seen as an effective place of refuge for PWD, helping to explain why they are the least likely to evacuate (King et al., 2019).

PWD are often reliant upon informal networks of support during crises, with both positive and negative consequences. King et al. (2019) explain how in the Solomon Islands the family is the most important social unit and thus little awareness of PWD beyond these units exist. This may dissuade the government from engaging with PWD as they are viewed as being too small in number, and already insulated from disaster by such support networks (King et al., 2019). Such assumed dependence deteriorates when these networks themselves are affected by disasters (Peek & Stough, 2010), leaving PWD with heightened vulnerability in the face of inadequate external support. Indeed, some PWD may have no support networks at all, making them especially vulnerable and isolated (Lunga et al., 2019).

**PARTICIPATION**

Compounding the vulnerability of PWD is their lack of inclusion in DRR. Yet in spite of a growing body of research and policy initiatives there is little evidence that points towards inclusive DRR implementation in practice (Smith et al., 2012; Twigg et al., 2018). A 2013 UNISDR global survey of PWD found that 85.57% of survey participants from 137 different countries had not participated in community disaster management and risk reduction processes (UNISDR, 2014). The inclusion of PWD at all levels of DRR planning, implementation and crucially, feedback mechanisms is needed to ensure meaningful participation (Sloman & Margaretha, 2018). Yet how exactly DRR initiatives can be inclusive of PWD and honour the disability-activism phrase “nothing about us, without us” is little understood (Sloman & Margaretha, 2018). The barriers to participation remain high, and further perpetuates a cycle of disclusion and disproportionate impacts during crises. These barriers for PWD include stereotypes, social stigmas, and a lack of knowledge about disabilities, inaccessible meeting locations and inopportune meeting times, and exclusionary forms of communication.
Inclusive DRR management should be viewed as not only an equity goal, but as a practical goal, as universal design not only serves PWD, but all individuals in the community as well (Stough & Kang, 2015).

**EFFECTIVE INCLUSION**

Disability advocates argue that accurate data is a “first step towards inclusion” (Sloman & Margaretha, 2018). Yet, currently, PWD remain invisible due to a lack of data. Even when they are ‘counted’ the heterogeneity of impairments are often singularly categorised as ‘special needs.’ The process of data collection must therefore include PWD to avoid such problematic portrayals. For PWD to participate in disaster management, its processes will need to change to be inclusive of people with different functionings. This requires the recognition of the diversity of PWD, and the dismantling of ableist norms in DRR processes. A benefit of the DRR process is the ability to utilise longer time frames to ensure thoroughness, representation and inclusion. DRR practitioners should take advantage of this to incorporate new forms of communication and listening thus ensuring inclusivity (Pyke & Wilton, 2020). As there is no single DRR strategy that will suit all impairments, it is important to recognise the heterogeneous capabilities, vulnerabilities and needs of PWD, and to be inclusive and representative in the planning processes (Ronoh et al., 2015). Inclusivity in DRR planning and implementation also requires the understanding that the experience of PWD intersects with other identities, including age, ethnicity, class, sexuality, and gender (GFDRR, 2017; Stough & Kang, 2015; Ton et al., 2019). Inclusion of PWD in DRR practices involves challenging stereotypes in everyday-life and changing policies from those that “help the disabled” to those which alter the environment that disabled them (Ronoh et al., 2015). Inclusion of PWD creates space for effective co-production of knowledge and practices, recognising that PWD are knowledgeable about their needs and the solutions that will be most effective in reducing their risk (Stough & Kang, 2015). Emphasising the capabilities of PWD, and enhancing individuals’ rights through shared decision making, program implementation, and inclusive and representative feedback mechanisms should be prioritised in DRR (Pyke & Wilton, 2020).

**POWER AND DECISION-MAKING**

Prioritising the inclusion of PWD should be integral to the decision making processes. The UN argues that exclusion from the decision making process in DRR helps explain the disproportionate vulnerability of PWD (Stough & Kang, 2015). The routine exclusion of PWD from policy formulation perpetuates their invisibility and makes it difficult to mainstream disability-inclusive policies in global DRR policy which guides national and local practice. The Yokohama Strategy and Plan of Action produced at the first UN World Conference on Disaster Risk Reduction (WCDRR) in 1994 did not reference PWD, disability-associated terms or themes such as accessibility or universal design (Stough & Kang, 2015, p. 142). Despite the recognition of other vulnerable groups, namely gender
and class in the second WCDRR in 2005, disability was again absent (Stough & Kang, 2015, p. 142). Evidently, PWD have, and continue to be, disempowered and excluded from making decisions about their own lives.

DECISION-MAKING AT SENDAI

Since the above conferences, the SFDRR produced at the third WCDRR in 2015 contained five distinct references to PWD and two additional references to universal design policies (Lockwood & Tardi, 2014, p. 434). Sendai thus represents the first time PWD and their advocacy organisations were recognised as legitimate stakeholders and actors in the creation and implementation of DRR policies (Lee & Chen, 2019; Lockwood & Tardi, 2014; Stough & Kang, 2015). This can be accredited in part to the nearly 200 PWD participants at the conference, which ensured that PWD had a voice and decision making authority (Stough & Kang, 2015, p. 141). Additionally there is consensus among scholars that Sendai’s success can be attributed to the Disability Caucus consisting of six disability advocacy and stakeholder groups which included disability on Sendai’s agenda (Lockwood & Tardi, 2014; Stough & Kang, 2015). The recommendations from the Disability Caucus show that PWD are critical in assessing the design and implementation of DRR (Stough & Kang, 2015, p. 145). This is important for increasing the decision making capacity of PWD since organisational advocacy can at times be more beneficial than individual agency, as evidenced by the influence of the Disability Caucus (SFDRR 2015-2030 | UNDRR, n.d.). Ultimately, this indicates that the inclusion of PWD is impactful.

Despite the significant contribution of SFDRR, many of Sendai’s policies have yet to be put into practice. For example, Taiwan’s strategies to aid PWD in disasters are still top-down, as there are no mechanisms established for a risk communication interface that includes PWD as active participants (Lee & Chen, 2019, p. 11). Similarly, despite regulation No. 14/2014 adopted by the Indonesian Disaster Management Agency that promotes active participation of PWD in all cycles of planning, implementation and monitoring of DRR programs, the low participation of Disabled People’s Organisations (DPOs) indicates that the engagement of the disabled community in Indonesia remains superficial (Pertiwi et al., 2019, pp. 1423–1424). Evidently, Stough and Kang (2015) were right to be hesitant, as there is often a gap between international policy and subsequent practices at national and local levels.

COMMUNICATION AND DISSEMINATION

The culmination of vulnerability, lack of participation and disempowerment is felt acutely in the practicalities of EWS, most specifically in the communication and dissemination of warnings. When a natural hazard is detected there is a crucial period of time in which the damage it causes to human life can be limited - crucial to this is how warning messages are distributed (dissemination) and what information they
contain (communication). Broadly put, communication and dissemination is about providing access to reliable and timely disaster early warnings to all members of an affected community (Dion & Qureshi, 2014), in a way that is understandable, actionable and accessible (Akwango et al., 2017). For example, if an effective EWS had been in place before the 2004 Indian Ocean tsunami, it is estimated that thousands of lives could have been saved (Alias et al., 2020; Sullivan & Häkkinen, 2011). Despite this, little academic or grey literature dealing directly with warning communication and dissemination in the context of disability currently exist.

COMMUNICATION AND DISSEMINATION FAILURES

Given differing societal and disaster contexts, there is no panacea for disseminating warning information. Currently, there are countless mechanisms for disseminating disaster warnings around the world, including but not limited to: audio, visual, technological, and community-based methods. All have their merits, and the use of multiple mechanisms together may increase their efficacy. Despite this, all are fundamentally limited for PWD. Evidence from disasters occurring since 2010 suggest that dissemination methods often fail not only to reach significant portions of populations but also to adequately communicate their message, frequently leading to confusion over the level of risk and how to act (Akwango et al., 2017; Alias et al., 2020; Cohen et al., 2014; Rahman et al., 2013). In terms of coverage, Alias et al. (2020) found that only 56% of affected people in Kelantan, Malaysia received warning of an impending flood in 2014. In this case, warnings were disseminated via TV news broadcasts, a method which relies not only on access to a television, and to have it turned on at the time of the warning, but also to be able to hear and understand the message. The disproportionate levels of poverty faced by PWD may also exclude them from having access to necessary technologies. These barriers make clear the need to address the method and content of disaster warning mechanisms to effectively reduce the impact of hazards.

INACCESSIBLE COMMUNICATION AND DISSEMINATION

Warning methods, across most disaster contexts, are inadequately designed to meet the needs of PWD (Dion & Qureshi, 2014; Sullivan & Häkkinen, 2011). Building on the social model of disability, it is evident that PWD are not inherently disabled, but are made ‘disabled’ as a result of structural failures to remove barriers to accessibility (Priestley & Hemingway, 2007). These challenges of dissemination are compounded by the heterogeneous nature of disability and the variable ways PWD receive and understand information (Sullivan & Häkkinen, 2010). Additionally, intersectionality of identities must also be accounted for in communication and dissemination. Where needed, early warnings must be made accessible in multiple languages to account for local or ethnic minority language diversity. Thus, there is no single policy or action which can uniformly benefit all PWD. For example, an inclusive warning mechanism for those with visual impairments to receive information (i.e. audio warnings), would not benefit
those with hearing impairments. Alias et al. (2020) found that the majority of their participants indicated TV as their favoured method of disaster warning dissemination. Yet visual warnings are only useful if they can be easily understood, and therefore exclude those with visual, learning or some cognitive impairments (Dion & Qureshi, 2014). Carby (2015) found in their focus groups that commercial media broadcasts in Jamaica did not cater to PWD. One of their participants with a hearing impairment reported being able to watch an incoming hurricane reported on the screen, but being unable to understand its severity nor how to keep safe, as it lacked text descriptions or closed captioning. This example makes clear the need to focus not just on methods of dissemination, but also content of communication.

EXAMPLES OF TECHNICAL DISABILITY INCLUSIVE DISSEMINATION

Recent technological innovations present a number of promising possibilities for inclusive warning mechanisms. In Japan, for example, accessible information dissemination technology has been developed and is in use in Urakawa, a city on the southern Pacific coast of Hokkaido. The Digital Accessible Information System (DAISY) is able to present text based, visual, and auditory information on personal computers and portable devices, essentially reading aloud, or interpreting, disaster warnings, and is useful for persons with visual or cognitive disabilities.

The Disaster and Emergency Warning Network (DEWN) (see Figure 3) is another system that represents a great deal of potential for disseminating warning messages to PWD and the population at large (Wijesinghe et al., 2011). DEWN is a dissemination mechanism developed in Sri Lanka that connects users to a national emergency alarm centre, which then sends alarm warnings to both mobile phones and alarm devices called RADs (see Figure 3 for architecture). Though not necessarily designed with disability in mind, DEWN has the potential to overcome a number of issues for PWD; for example, the RAD has both an audible alarm and a flashing light alert, can be tuned into a radio receiver, and has a 'one-touch' callback facility to an emergency hotline. This means people with visual and auditory impairments can be alerted, and the call-back facility would allow people with cognitive disabilities to have warning messages described to them in understandable formats/language. The RAD also has an FM radio built in, to aid the devices integration into day-to-day life. DEWN therefore represents a great deal of potential for disseminating and communicating warning messages to
PWD and the population at large. Questions remain, however, about the financial cost of the device, and the physical infrastructure required to operationalise it. More research is needed.

**RESPONSE**

In contrast to dissemination, response involves the steps taken immediately after the occurrence of a disaster which are focused on rescue activities to save lives and to meet the immediate needs of the population (Uimusova et al., 2009). In most cases, central, regional, and local governments are responsible for responding to disasters (Fox et al., 2007). Response phases after disasters are heavily influenced by the factors discussed above and feed into an individualisation of response.

**INDIVIDUALISING RESPONSE**

During the immediate aftermath of a disaster, little external assistance for PWD is expected for various reasons, and consequently first responses remain at individual or at most community levels (Uimusova et al., 2009). In these situations, the assumption is that PWD should simply adjust to and accept the built environment and to individually prepare for and respond to emergencies by “understanding the risk and knowing their abilities” (Christensen et al., 2007, p. 253). This is rooted in medical models of disability. Such an approach shifts the responsibility of preparing and responding to disasters from the government to the individual. PWD are thus made responsible for actions such as collecting information, accessing shelter and food on their own, planning escapes, and asking for assistance (Christensen et al., 2007) - actions which they may or may not be able to do independently. This idea, that disability is a problem to be solved individually, leads to the ignorance of underlying risk factors which make PWD more vulnerable (Christensen et al., 2007). Although it is true that some individual effort is needed, and indeed many PWD have this capacity, it is based on the false assumption that such efforts occur in a barrier-free environment (Lee & Chen, 2019). As a result, individualised responses to disasters are a significant barrier to the required institutional reform from above, while also acting as a barrier to PWD asking for assistance (Gartrell et al., 2020).

**REAL-LIFE CHALLENGES FOR PWD IN RESPONSE PHASES**

Disasters are known to have disproportionate effects on the population often in accordance with various identities such as gender, age, and ethnicity (Gartrell et al., 2020). Some of the studies have identified real-life challenges that PWD face during and after disasters. First, information and communication issues immediately after disasters were a big barrier for PWD. People with visual impairments in the aftermath of the Christchurch earthquake in New Zealand reported that the quality of information broadcast through the radio was very poor, and that they experienced further problems with power failures that prevented collecting information and communicating for
support (Good et al., 2016). The government’s increasing reliance on the GPS system and telephones to track people and disseminate critical information worked as another barrier as it was difficult for them to use (Good et al., 2016). The next big issue was related to a lack of personal and agency support. Those who were interviewed after the Christchurch earthquake stated that no agency support was available during the aftermaths of the earthquake and promised agency support became available only after months (Good et al., 2016). Women with disabilities in Cambodia also reported that they had no prior knowledge of whom to ask for support after disasters and some even reported that they did not know that assistance was available (Gartrell et al., 2020). Another significant issue was the limitation of mobility after disasters, which lead to several other problems such as being unable to evacuate to designated shelters, requesting assistance, and receiving medical support (Good et al., 2006). In cases of Cambodia, women often resorted to staying home or praying at home in fear rather than actively seeking assistance (Gartrell et al., 2020). Interviews in New Zealand also showed that familiar landmarks and pathways being destroyed greatly influenced the mobility of people with visual impairments, which decreased their sense of independence and increased their level of vulnerability (Good et al., 2016). Many of the interviewees were ready to provide more testimonies if the challenges they faced would be resolved in the future (Good et al., 2016).
PART 2: KEY INTERVIEW FINDINGS

SUMMARY OF INTERVIEW FINDINGS
Conducting twelve key-informant interviews added a richness to this report that a literature review alone could not provide. The key findings from these interviews can be grouped into four thematic areas:

(1) POLICY VS. PRACTICE
- Theoretically effective policies are poorly implemented and thus rendered ineffective in practice. Often with a lack of accountability.
- There is a tendency towards implementing ineffective and unsustainable short-term projects.

(2) ABLEISM
- Ableist approaches to disabilities are embedded within societies and organisations, serving to exclude PWD and significantly increase their vulnerability.
- Ableism is not adequately recognised within institutions and structural change is required.

(3) DATA AND DEFINITIONS
- PWD are ‘invisible’ to policy makers as they are underrepresented in statistics due to both a narrow understanding of disability and the social stigma associated with it, all of which makes people reluctant to be identified as disabled.

(4) INTERSECTIONALITY AND INDIVIDUALISM
- The intersectionality of disability is not fully recognised
- PWD are not treated as individuals with rights that should be empowered and therefore the decisions made about them do not reflect their heterogenous experiences.
POLICY VS. PRACTICE

The overwhelming consensus from the interviewees was that there remains a frustrating lacuna between DRR policies and the EWS in place for PWD and their implementation. Interviewee 8 sums up a sense of frustration that “there has been a convention for over a decade now [the CPRD], and I can’t believe I’m having the same conversations.” Echoing this, Interviewee 10 describes how “there are enough reports now... we know what the issues are for PWD in these settings. We have loads of recommendations that are really practical in some places,” but in spite of this “people are still doing what they were before, and maybe collecting a bit more data.” Clearly the creation and discussion of policy greatly outweighs the extent to which it is meaningfully implemented. For policies to effectively achieve change in the lives of PWD, there needs to be accountability. In this sense, there must be “legislation that can hold organisations and governments accountable for what they are doing, or potentially other forms of monitoring such as citizen accountability” (Interviewee 8). Consequently, there remains a disjuncture between how organisations say they will monitor impact and their actions, rendering many policies toothless (Interviewee 8). Furthermore, far too often these projects are limited to short-term fixes which do not achieve meaningful change and are often discarded in the long-run (Interviewee 5; 7). Organisations outside of local communities have a tendency to impose issues on a community which may not reflect their lived realities, and so whilst communities may be on board for the duration of the project, once it ends “things don’t really change” (Interviewee 1), which sums up the lack of faith in policy making.

ABLEISM

Another key barrier identified by several interviewees was attitudinal, with ableism present across societies and within organisations. Ableism is not exclusively about “deliberate exclusion” but rather a lack of consideration of the needs of PWD (Interviewee 9). Ableism is widespread throughout society, and governments “often exclude PWD because they are saying they are not fit to be in our society” (Interviewee 1). PWD are problematically viewed as ‘additional’ when it should be obvious that PWD are “just human beings” like any other (Interviewee 11; 10). “Even where PWD are considered, the focus tends to be mainly on those ‘observable’ disabilities, i.e. physical impairments such as limblessness. Cognitive and mental impairments are not so well understood, and as such are rarely thought of in planning and disaster response”
are considered, the focus tends to be mainly on those 'observable' disabilities, i.e. physical impairments such as limblessness. Cognitive and mental impairments are not so well understood, and as such are rarely thought of in planning and disaster response" (Interviewee 3). PWD "are seen as 'charity cases,' and lack agency, which affects the likelihood of their inclusion through no fault of their own" (Interviewee 3). Such problematic attitudes extend to NGOs, with Interviewee 10 describing how ableism is unconsciously "embedded" within aid agencies, akin to institutional racism, for example. Moreover, several interviewees recalled problematic notions from NGOs which dismissed disability as not "something they work on" (Interviewee 11), or that "we’ve got so many people to focus on, we can't focus on PWD" (Interviewee 10). Evidently, this societal discrimination is "called out about sexism and racism, but not about ableism" (Interviewee 8). The result of ableism is that PWD are not considered when a disaster occurs, excluding them from support and increasing their vulnerability (Interviewee 3; 9). Disability transformative DRR and EWS requires a "systemic change," one which tackles the systemic ableism present within society and organisations (Interviewee 6; 8; 10; 11).

DATA AND DEFINITIONS

For policy to translate into practice, and to overcome ableism, better data is needed. "If you’re going to change policy, decision makers need to have robust and extensive data. It doesn’t mean they’re going to make good decisions ... but without it there is no chance" (Interviewee 9). Ableist assumptions mean that disability is poorly conceptualised as both a problem and as something to be fixed, mirroring the medical model of disability (Interviewee 3; 5; 9). Subsequently, data collection is impeded by ableism while a lack of data perpetuates it. This likely explains why "plenty of people who have a disability don’t disclose it, and for good reason" (Interviewee 8). People may view identifying as disabled as having harmful consequences, something that Interviewee 10 describes as "self-stigma" - a phenomenon caused by the internalisation of ableism. The constraints on identification result in an underrepresentation of disability prevalence (Interviewee 8). Governments then use this "as a justification for not then trying to reach the people who need support" (Interviewee 11), which is why "[PWD] are invisible to most decision makers" (Interviewee 9). Many interviewees thus pointed to the social model of disability as necessary to make PWD visible in society (Interviewee 3; 9), since it would help create a more accurate depiction of disability prevalence and ensure that support for PWD is better targeted and their rights are more robustly advocated for.

“If you're going to change policy, decision makers need to have robust and extensive data. It doesn't mean they're going to make good decisions ... but without it there is no chance.”
INTERSECTIONALITY AND INDIVIDUALISM

A final prerequisite for systemic change is a greater understanding of intersectionality in disability studies, and an appreciation of the individual needs and capacities of a radically diverse group of people. Interviewee 8 eloquently explains “we don’t assume that all women are the same, or that all issues of gender are pertaining to women. So why do we do it with disability?”. They continue, “the challenge is balancing the nuances for each specific group with the kind of overarching set of principles, which is not unique to disability” (Interviewee 8). Reflecting ableist attitudes, many assume that disability issues are specialised when in reality “most of the good practice isn’t… It’s things like understanding intersectionality; how different factors intersect, and how they shape risk” (Interviewee 11). Whilst an appreciation of intersectionality is slowly building when it comes to disability, its application is still “quite theoretical” (Interviewee 11). Furthermore, when PWD are treated as a uniquely homogenous group, their individual needs, capacities and vulnerabilities are assumed to be the same, when in reality there is massive heterogeneity (Interviewee 11). Recognising the individuality of PWD is vital and can be the stepping stone for a rights-based approach (Interviewee 10). The denial of the rights of PWD, both implicitly and explicitly, further fuels ableist assumptions and ultimately “without adequate individualised support PWD are unable to make decisions for themselves and the danger of this, especially in disaster situations, is that they can be left behind” (Interviewee 7). Recognising PWD as individuals is key, as it will allow PWD to challenge the lack of policy implementation, tackle societal ableism, and subsequently improve data collection to recognise the intersectional needs of PWD.

“We don’t assume that all women are the same, or that all issues of gender are pertaining to women. So why do we do it with disability?”
PART 3: CASE STUDIES

SUMMARY OF CASE STUDIES
The two case studies on Zimbabwe and Nepal provide context specific and real challenges that PWD face on the ground. This section identifies barriers specific to each country and ways to move forward based largely on interviews and existing background literature.

ZIMBABWE
A society-wide negative attitude to disability, limited inclusion of PWD in policy planning, and the absence of DRR frameworks designed for PWD were found as the main challenges.

NEPAL
A systemic underestimation of data on disability, a narrow definition, and the consequent lack of inclusion and representation were found as the main barriers for effective EWS for PWD.
BACKGROUND

Exacerbated by climate change, Zimbabwe faces periodic droughts, floods and cyclones. Most recently was Cyclone Idai (2019), which affected 270,000 individuals (Mhlanga et al., 2019, p. 47). As an agrarian economy, Zimbabwe is acutely vulnerable to extreme climate events that disrupt seasonal livelihoods (Bongo et al., 2013, p. 1). PWD, subject to society-wide ableism, are one of the most vulnerable groups to such calamities due to the potential destruction of livelihood assets and social capital (Bongo et al., 2013, p. 7). There was once much hope that Zimbabwe could be one of the leading forces for disability rights in Africa; the promulgation of the Disabled Persons Act of 1992 positioned Zimbabwe as a model country on the issue (Manatsa, 2015, p. 25). Government legislation throughout the 1990s reaffirmed that the needs of PWD should be integrated into all national plans and programs, and that all public places be made more accessible (Mhlanga et al., 2019, p. 49). This inclusion attempt was exemplified by the Zimbabwe Inter-Censal Demographic Survey in 1997 which identified that 20% of the population had a disability (Choruma, 2006). Yet, in the last 20 years, little progress has been made. This was echoed throughout the interviews: “PWD are invisible to official government organisations” (Interviewee 3); “communities don’t look at [disability] as an issue which needs to be addressed” (Interviewee 1). Moreover, Interviewee 5 notes that “Zimbabwe’s physical infrastructure is poor quality; roads and pavements are so inaccessible for people who use wheelchairs”, indicating that the aspirations of the earlier government reports have not borne practical results.

BARRIERS/CHALLENGES

Echoing one of the key findings of the literature review, the first barrier that PWD face throughout Zimbabwean society is “negative attitudes towards people with disabilities, in terms of how they are thought of, referred to and treated” (Interviewee 3). Reflective of the society-wide ableism, negative beliefs on disabilities such as the association of disability with witchcraft, maternal promiscuity and taboos, can facilitate ostracisation of PWD by their families and communities, which in turn affects the visibility of PWD in demographic data (Choruma, 2006, p. 7). Furthermore, these negative attitudes hamper the ability to “achieve meaningful change in disability planning and policy” (Interviewee 5). For example, there is the belief that PWD cannot make decisions for themselves, which is why economic development schemes in Zimbabwe have bypassed PWD. Mtetwa (2016) illustrates the story of a group of women with visual impairments who were denied a share in land reforms for their businesses because government officials deemed them incapable of success. This is a particular challenge for EWS, as one interviewee noted that in communities people are reluctant to share early warning protection measures and policies with people who have cognitive disabilities on the basis of them being “mad” (Interviewee 1).
A second challenge is the extremely limited inclusion of PWD in policy planning. As one interviewee highlighted:

“Zimbabwe’s Department of Public Affairs is staffed by people who do not have disabilities, from top to bottom. This is reflective of a widespread institutional deficiency in public administration. As such, disability programming relies on ‘imagination and assumption’. The people who sit in the House of Assembly – the most powerful body in Zimbabwean Parliament – have no ‘disability face’, meaning there is no representation of PWD. As such, disability is very rarely considered in new legislation.” (Interviewee 5)

Even with the adoption of the Disabled Persons Act 1992, there have been no specific governmental policies to ensure its implementation (Tarisayi, 2014), leading to a gap between policy and practice. Evidently, such exclusionary and top-down approaches have led to poor resilience and preparedness, as Zimbabwean DRR frameworks have been designed for nondisabled people (Bongo et al., 2013, p. 1). Compounding this, interviewees pointed to the fact that there is little coordination between governments and NGOs on the ground, and that any progress they make perishes once the project is over (Interviewee 1; 3).

The last main challenge for PWD in Zimbabwe is that there is no “comprehensive disability disaster risk management plan” (Interviewee 5). The current DRR framework fails to include the most marginalised and excluded populations, including PWD, the terminally ill, extreme poor, the elderly, children and ethnic minorities (Bongo et al., 2013, p. 1). This is particularly worrying considering that access barriers are more pronounced during disasters for PWD. For example, Tarisayi (2014, p. 1) emphasises the destruction of social capital, which is especially problematic for PWD, since social networks established prior to the disaster are subsequently uprooted. Additionally, in the relocation process, the needs of PWD are overlooked. For example, trucks mobilised in village relocations after the floods in the Masvingo Province had no wheelchair accessibility (Tarisayi, 2014, p. 1).

MOVING FORWARD IN ZIMBABWE

A common suggestion for EWS and DRR policies is the focus on community-based policies (CBP). One interviewee discussed the use of “knowledge workers” in previous development schemes, they were “school dropouts in certain communities. [Organisations] would come and train them on various policies, sending them back to the
community where they were trusted" (Interviewee 1). The interviewee suggested a similar scheme could be used to accommodate PWD specifically. Jairos Jiri, a local organisation mentioned in the interviews is involved in CBP projects to meet the needs of PWD through grassroots participation (Bongo et al., 2013, p. 1). Making use of CBP is key in representation as noted by one interviewee, *“early warning systems at the local level [are] based on indigenous knowledge”* (Interviewee 1) and in some cases *“traditional village communities are more aware of PWD than official government organisations; ... community leaders will ensure PWD are catered for if problems arise”* (Interviewee 3). It is essential to utilise and build on preexisting family and local community support systems to reduce vulnerability (Bongo et al., 2013, p. 10), especially as involving local communities is an essential element of effective EWS. Interviewees called for greater inclusion of PWD in program and policy design, implementation and evaluation, arguing that pressure needs to be put on the Zimbabwean government and those working in DRR to improve disaster management to do this.

**NEPAL**

**BACKGROUND**

Similarly to Zimbabwe, Nepal faces many natural hazard related disaster risks, including earthquakes. In the aftermath of the 2015 earthquake, PWD struggled to access mainstream relief and recovery programmes, something which was especially true for women and ethnic minorities with disabilities (Guidry-Grimes et al., 2020; Lord et al., 2016). Inspired by this failure, a new constitution was created in the same year which affirmed PWD rights to equality, social justice, and representation, while the 2017 Rights of the Persons with Disabilities Act adopted a rights-based approach to disability (United Nations Human Rights Report, 2018). Today, Nepal’s approach to the governance of disasters is enshrined in the Disaster Risk Reduction and Management Act of 2017 and is outlined in the National Policy for Disaster Risk Reduction 2018. Within this policy, disability is mentioned twice, once in regards to access, representation and meaningful participation and then in regards to disability friendly infrastructure (Government of Nepal, 2018). However, the increased attention and policy aimed at including PWD in DRR and society more generally has not yet been transformed into practice, and disproportionate barriers and challenges across the entire disaster cycle remain.

**BARRIERS/CHALLENGES**

Nepal has a *“critical”* need for more effective data collection (Interviewee 4; 9; 12). The number of PWD in Nepal is systematically underestimated, with the prevalence of disability being recorded as 1.94%. Whilst similar prevalence is recorded in neighboring countries, this number is far below the global average of 10-20% (Gvetadze, 2017;
Practical Action Consulting – Towards Disability Transformative EWS

Landry et al., 2016; Lord et al., 2016) and the underestimation of prevalence is common in Lower Income Countries for myriad reasons (Eide & Loeb, 2016). Nepal in this case is very much the rule, not the exception. The collection of better data alone is not enough. It is crucial to ensure that whomever is “collecting the data has the sense of duty or responsibility to at least go back and provide PWD with some advice or assistance” (Interviewee 8). Currently, the Nepalese government only recognises 10 categories of impairment (see Figure 4) and those who fall outside these categories are not recognised as disabled, compounding the inaccurate picture of disability in Nepal, and a costly absence of government support (Interviewee 6; 12).

Consequently, many Nepalese PWD “still don’t think themselves disabled” and as such choose not to get government issued ID cards (in itself hard to obtain) which entitle them to support (Interviewee 6). The lack of data on PWD in Nepal creates barriers to inclusion and representation in DRR programs, and further blocks individual access to critical healthcare and support.

Secondly, Nepal’s limited definition of disability fails to account for the country’s complex heterogeneity and intersectionality. Interviewee 12 highlights the importance of “human diversity” both in the CPRD and within the Nepalese constitution which “clearly says that Nepal is a multicultural, multi-ethnic, multi-religious, [and] multilingual country.” This limited conceptualisation of disability is reflected in government policy and programming and perpetuates compartmentalised approaches to disability which treat disability as a specialist issue which is not intersectional with other groups in society (Interviewee 12). Current approaches in Nepal only use “framing from an impairment
perspective [but] if you go through different layers of identities, those layers of identities are providing more adverse realities and experiences faced by people in different contexts” (Interviewee 12). Such intersectionality resulting in ‘double discrimination’ is often experienced by women and girls, people with cognitive disabilities and people from ethnic minority populations (Dhungana & Kusakabe, 2010; Guidry-Grimes et al., 2020; Lord et al., 2016). Interviewee 6 noted that PWD in rural areas face additional exclusion, emphasising that, “Kathmandu has many institutions relating to people with disabilities … but the people who are living in very remote places, they can’t come to [the city]”. There is also limited translation of information into local languages which further marginalises and excludes PWD from ethnic minorities (Interviewee 6; Lord et al., 2016).

The third barrier identified is a lack of representation and inclusion (Guidry-Grimes et al., 2020; Lord et al., 2016). As Interviewee 12 articulated, “the whole narrative has been defined by people who are in power. There is still a gap of meaningful participation of people with disabilities in all spheres of life”. Consequently without this voice of experience, disability is erroneously perceived to be an overly technical, complex and resource intensive issue (Gvetadze, 2017; Lord et al., 2016). Importantly however, inclusion is only effective when it is meaningfully participatory and represents the diverse identities of PWD; “by integrating a few persons with disabilities, that does not mean that you are integrating the whole disability” (Interviewee 12). It is important to recognise that “systems of power [operate] even within groups of DPOs” (Interviewee 4). Generally “people with disabilities are taken as a token representative” and the lack of meaningful representation of PWD and DPOs remains a significant barrier to disability transformative EWS (Interviewee 12).

MOVING FORWARD IN NEPAL

Literature and interviews reiterate the importance of meaningful inclusion and representation of PWD, which reflects their heterogeneity, at all levels of DRR program and policy development. Transforming Nepal’s existing DRR policies into effective practice remains a key challenge (Interviewee 4; 6; 12). Improving the collection and use of data to reduce the number of PWD who are ‘invisible’ to policy makers, and to increase participation is a recommended first step. To move forward greater understanding of intersectionality within the blanket category of disability is required (Interviewee 12). DRR and EWS in Nepal must “look at disability from a very inclusive perspective”, encompassing the intersection of various identities (Interviewee 12). PWD must be at the centre of the decisions impacting their lives and their capacities need to be recognised and supported (Interviewee 4; 12). Interviewee 4 noted that DRR policies and practitioners should give PWD space to define the hazards and vulnerabilities they
face themselves because “when it comes to thinking [about] intersectionality, they're going to be able to give you a much more precise understanding and definition of what vulnerabilities people like them could experience in the context of a disaster.” When PWD are included they will be able to challenge the limited definitions, poor data and lack of meaningful representation in DRR and EWS planning and implementation in Nepal.
PART 4: MOVING FORWARD

SUMMARY OF MOVING FORWARD
The barriers and challenges highlighted within the literature review, case studies and by the interviewees are significant, but not insurmountable. This section posits several key ways of moving forward and represents a synthesis of the knowledge drawn from the literature and interviewees. These pathways to disability transformative EWS and DRR practices can be grouped into four key sections;

(1) TWIN-TRACK APPROACH
Implementing specific targeted practices while aiming to achieve broader structural change based on the universal approach for disability inclusiveness.

(2) UNIVERSAL DESIGN AND DISABILITY TRANSFORMATIVE EARLY WARNING DISSEMINATION
Adopting universal designs that create accessible products and environments for the benefit of all, in everyday life and in terms of disaster preparedness.

(3) BEYOND DEFINITIONS
Going beyond definitions of disability, by addressing the current socio-economic structural barriers to change.

(4) MEANINGFUL PARTICIPATION
Recognising the capabilities of PWD through a rights-based approach, through ensuring meaningful participation, keeping in mind, “nothing about us, without us”.
The first fundamental step involves adopting the twin-track approach, which is a practical framework that has been used in promoting effective disability inclusion (Interviewee 11). It involves 1) taking a universal approach while simultaneously; 2) implementing targeted interventions at the local and community levels (Interviewee 11). Therefore the road ahead for disability transformative EWS and DRR practices involves strategies aligned with the twin-tracks.

**UNIVERSAL APPROACH**

The universal approach shifts away from the idea of ‘special responses for special needs’ which is largely based on the minority approach, and accepts a wider range of ‘normal’ that is applicable to all humanity (Bickenbach et al., 1999) Here, the minority group approach is a perspective that views PWD as a minority group, and precisely because they are a minority, they have been denied the basic civil rights they are entitled to due to institutional and systemic discrimination (Bickenbach et al., 1999). Thus, advocates of the approach like Hahn (1993), argue for legal solutions such as anti-discrimination laws that can guarantee the protection of civil rights (Hahn 1993, in
Bickenbach et al., 1999). On the other hand, the universal approach emerged based on the criticisms of the minority group approach. Although the minority group approach had allowed considerable progress in promoting civil rights of PWD during its initial application in the 1980s, it has had major criticisms as time went on. Zola (1989, p. 420) argues that the minority group approach is only a short-term solution which reinforces only the medical conception of disability and consequently fixes a dichotomy between PWD and the nondisabled people, where in a world of finite resources, PWD are “pitted against the needs, wants and rights of the rest of the population.” Consequently, a contrasting universalistic strategy emerged with Zola who argued that a long-term shift should be aimed, where universal policies recognise “that the entire population is at risk of the concomitants of chronic illness and disability”, therefore accepting that disability is not a demarcation of a different group of humanity, but only a part of an “infinitely various but universal feature of human condition” (Bickenbach et al., 1999, p. 1182).

Implementation of policies based on this approach is the main goal of the first track. Despite the criticisms of top-down level policies, it is essential that inclusive policies are implemented at the highest level to ensure change. Once large international organisations such as the World Bank, or the UN start mainstreaming disability inclusivity through their policy, it is highly likely that others will follow suit (Interviewee 11). Moreover, measures such as funding restrictions for those lacking inclusivity frameworks would ensure NGOs and organisations take inclusion more seriously (Interviewee 11). Yet, adopting the universal approach is not merely “ticking-the-box, but transforming our fundamental perceptions of disability and inclusion, resulting in a fundamental paradigm shift” (Interviewee 8).

TARGETED PRACTICE
Parallel to the universal approach are specific targeted practices at community and local-levels. One interviewee illustrates how the twin-track approach might be adopted during the delivery of food to a community post-disaster:

“If [one is] delivering food to everybody, [they must] think about [individual] access in different ways, such as [access for] PWD or women in the environment, while simultaneously having a targeted practice that involves, for example, allocating specific budgets for certain impairments, because we know that this is something that will particularly help a certain group of people with disability.” (Interviewee 11)
UNIVERSAL DESIGN AND DISABILITY
TRANSFORMATIVE EARLY WARNING
DISSEMINATION

A Universal Design (UD) is an application of the universal approach (above) that ensures the design of products, built environments, and transportation is suitable for universal usage. It involves creating a world which can be accessed, understood and used to the greatest extent possible by all people regardless of their functioning. To achieve this, PWD must be involved at all stages of the design process (see meaningful participation below), and effective mechanisms for continuous feedback must exist.

There are seven principles of UD (Woodward, 2017):

1. Equitable Use: does not disadvantage or stigmatise any group of users.
2. Flexibility in Use: accommodates a wide range of individual preferences and abilities.
3. Simple, Intuitive Use: it is easy to understand, regardless of the user’s experience, knowledge, language skills, or current concentration level.
4. Perceptible Information: communicates necessary information effectively to the user, regardless of ambient conditions or the user’s sensory abilities.
5. Tolerance for Error: minimises hazards and the adverse consequences of accidental or unintended actions.
6. Low Physical Effort: can be used efficiently and comfortably, and with a minimum of fatigue.
7. Size and Space for Approach & Use: appropriate size and space is provided for approach, reach, manipulation, and use, regardless of the user’s body size, posture, or mobility.

Adhering to these principles in the design of products and infrastructure can save lives of PWD before, during and after disasters. The built environment in particular can pose challenges to safe evacuation for PWD. More inclusive design of the physical world can “make it easier to evacuate... [and] move through space for everyone.” (Interviewee 4).

In practice, “applying the principles of Universal Design means developing early warnings, evacuation policies and standard operating procedures that are inclusive of and accessible to everyone, including PWD” (Dion & Qureshi, 2014, p. 43). Here there is limited progress; neither the literature or the interviews were able to provide examples of communication and dissemination methods which had successfully warned, or
accommodated for the needs of, PWD in disaster settings, again indicating the strong need and opportunity to develop effective EWS by applying UD. Despite this, research in the field is growing. For example, Sullivan and Häkkinen (2010, p. 231), have established eight key guidelines required for a disability inclusive early warning dissemination project:

1. “Ensure any person will receive, understand, and be able to act upon information received in a timely manner.
2. Allow an individual to make an informed decision about lifesaving measures for themselves or those they care about.
3. Ensure that the ... model remains effective when parts of the technical infrastructure may fail or be under stress.
4. Facilitate learning and action for people with learning and cognitive disabilities.
5. Present potentially complex spatial directions to people with visual or cognitive impairments in a manner which can be understood.
6. Be able to alert people who are hearing impaired or in a noisy or shielded environment.
7. Anticipate that there will be linguistic differences in a country.”

BEYOND DEFINITIONS

Applying the twin-track approach to disability definitions is the next step forward. While defining disability is essential for data collection and inclusion in society, it can facilitate the stigmatisation of PWD. Therefore, looking beyond the current socio-economic structures that continue to oppress individuals with impairments is vital (Interviewee 2; 7; 8; 9; 10; 11). Society must be designed to incorporate the inclusion of all people, something which should be emphasised in DRR and EWS planning and implementation. As Interviewee 7 reiterated “what’s the cause of [disability] problems, does it exist within the individual or is the problem in society or the environment or other people’s attitudes or a lack of support or the policies and responses that we provide?” Therefore, it must be questioned if definitions of disability challenge the societal barriers that turn impairments into disabilities, or if they reinforce them. “The idea that disabled people have rights to be treated equally is important, but it’s important that it’s not reduced to just that. [One must] understand that it’s also environment, culture, structure and economics” (Interviewee 7). Emphasis must be placed on achieving systemic change (Interviewee 9; 10; 11). Evidently effective DRR and EWS programs should align with the twin-track approach by understanding the individual needs of members in a community and looking beyond definitions to UD programming that accommodates all levels of ability.
MEANINGFUL PARTICIPATION

The next step to ensuring inclusivity is meaningful participation. This requires a paradigm shift away from inherent vulnerability towards a recognition of capabilities and an emphasis on a rights-based approach to enhance individual empowerment. The disability activism phrase “nothing about us, without us” is key. Without meaningful participation of PWD and DPOs, research, programs and policy cannot adequately address their needs and desires (Interviewee 4; 5; 10; 12). Importantly, a rights-based approach emphasises the need for inclusion on the grounds of humanity itself, “it doesn't matter if people are vulnerable, or if they've got something they can offer the community, they’re also just a human being, within a central set of inherent rights that we've all agreed and signed up to” (Interviewee 10). Interviewees continuously highlighted the need for proper participation to ensure representation of the heterogeneity and intersectionality of identities that fall under the disability category. “Participation, meaningful, proper participation, not just consultation, and having that built into communities in practical work to establish EWS, or to deliver humanitarian assistance is maybe the best chance of capturing people who fall into [marginalised] categories” (Interviewee 10).

Furthermore, another interviewee noted that “when you think about [disability] from a rights perspective you are forced to think about the individual, which makes the chances of you being able to enable and extend rights to those in vulnerable settings, higher, because you're thinking about them as an individual rather than a homogenous group or a vastly incorrectly stereotyped group, which is what often happens with people who are older or have a disability” (Interviewee 11). Such focus allows for the recognition of individual needs and how to address these systematically, rather than the categorisation of ‘special’ needs which often perpetuates a tokenistic representation of PWD in the planning process (Interviewee 1; 11; 12). Thus, in effect “you actually speak to the people you want to target” and consequently “you go and reach out to them”, which is why “participation of PWD is key from the onset, then engagement and representation” (Interviewee 11). By centering voices of PWD and their representative organisations and understanding that they are their own best advocates, more effective EWS and DRR strategies can be put in place that will actually serve the needs of the entire community and will ultimately save more lives.

“It doesn't matter if people are vulnerable, or if they've got something they can offer the community, they’re also just a human being, within a central set of inherent rights that we've all agreed and signed up to.”
The Road to Disability Transformative EWS and DRR

The Twin-track Approach

Universal Approach
- Recognising the capabilities of PWD through a rights-based approach, thereby promoting and ensuring meaningful participation – not just consultation

Targeted Practice
- Simultaneously taking the universal approach and implementing targeted practices for transformation inclusion

Beyond Definitions
- Going beyond definitions of disability, by addressing the current socio-economic, environmental, cultural and structural barriers to change and inclusion

Universal Design
- [The Seven Principles]
  1. Equitable use
  2. Flexibility in use
  3. Simple, intuitive use
  4. Perceptible information
  5. Tolerance for error
  6. Low physical effort
  7. Size and space for approach & use

Meaningful Participation
- "Nothing about us, without us"
- Recognising the capabilities of PWD through a rights-based approach, thereby promoting and ensuring meaningful participation – not just consultation
CONCLUSION

To conclude, in seeking to understand the barriers and challenges faced by PWD in disasters, this report has highlighted how PWD are systemically forgotten, overlooked and marginalised. Overall it seeks to convey the fundamental fact that “disabled people are not the problem” (Interviewee 7). Whilst this may appear obvious, in reality the insidious presence of ableism is the barrier which underpins all other barriers to a truly transformative EWS. Akin to racism or sexism, ableism stigmatises and problematises disability, stripping PWD of agency and infringing upon their human rights. The significant contribution of this report has been to display how such neglect translates into disaster policy and practice. PWD are systemically disempowered and excluded within society and in decision making and are prevented from shaping the decisions made about them. When PWD are disempowered in this way, disability definitions become constrained by the perspective of the nondisabled, further reinforcing the false assumption that disability is a specialist issue. This exclusion and invisibility exacerbates the vulnerability of PWD in disasters, meaning the negative consequences are felt more acutely for an extended period of time. Tackling ableism therefore involves
a commitment to transformative societal change and the removal of underlying structural causes of disability.

While tackling ableism is the ultimate goal, practitioner organisations and disability experts have a responsibility to construct their programming around the needs and capabilities of PWD and to meaningfully include PWD in their design. In this regard the benefits of a twin-track approach are clear. It will have beneficial consequences as the scope of disability and the understood needs of PWD are broadened. It will encourage the development of UD as a core tenet of the universal approach, in addition to challenging what is meant by disability and so necessitate a move beyond limited definitions. More fundamentally it will ensure that PWD are meaningfully included as they are increasingly recognised as individuals with human rights. Furthermore, the combination of these factors will be significant in tackling ableism in society. Overall, ensuring that a twin-track approach is adopted is a strong foundation from which disability transformative DRR policies and EWS can be developed.

Building upon this and expanding from the broad recommendations in the executive summary, the following section outlines the practical recommendations for practitioner organisations and governments to develop disability transformative DRR policies and EWS.
PRACTICAL RECOMMENDATIONS

- Provide Disability Awareness training to all levels of organisational staff
  - Seek country specific Disability Awareness training
  - Ensure Disability Awareness training is part of onboarding processes for all new staff

- Provide basic training and education for first-responders of disasters, which mainly include the police forces, firefighters, emergency medical and rescue teams on disability so that they are aware of their presence and are prepared to safely respond to their circumstances and needs (Interviewee 6)

- Respect the diversity of PWD and focus on representation and participation of individuals with multiple identities (ethnic minority, PWD, gender, sexuality) to address the vulnerabilities and enhance the capacities of marginalised groups in EWS and DRR planning and implementation

- Ensure meaningful participation of PWD and DPOs at all levels of DRR processes and at all levels of decision making, including research, planning, design, implementation, response mechanisms and feedback-loops

- Ensure inclusion of PWD in community training schemes for EWS and DRR conducted by large international organisations such as IFRC and UNDRR (in past training schemes and reports, PWD are hardly ever mentioned)

- Provide local level basic education on daily safety measures such as fire safety to prevent small-scale emergencies that can create (further) impairments (Interviewee 6)
  - Work alongside local DPOs in all DRR processes. Identify what is already being done within a community and work to enhance these programs
  - Do not assume the hazards and vulnerabilities PWD experience. Ask them what they consider their vulnerabilities are (Interviewee 4)

- Utilise longer time-frames in DRR processes to be more inclusive of varied communication and physical abilities
  - Ensure DRR processes are communicated in multiple formats to meet the needs of PWD
  - Ensure DRR meetings are held in accessible locations at opportune times, or make the effort to meet PWD or their DPOs where they are to include them in DRR processes
• Identify and train “knowledge workers” in communities to identify the needs of various members of the community and to assist in data collection

• Be mindful and responsible with data collection. Ensure that it results in meaningful participation of PWD and that there is engagement with the community after data collection (Interviewee 8)


UNDRR. (2013). UN global survey explains why so many people living with disabilities die in disasters.


WHO. (2002). Towards a Common Language for Functioning, Disability and Health ICF.


APPENDIX: REFLEXIVITY AND ADDITIONAL CONCERNS

Given how strongly we advocate for the inclusion and representation of PWD, we feel it necessary to discuss in more depth our role as nondisabled researchers. Many have justly argued that traditional research about disability has disempowered disabled participants by placing their knowledge into the hands of the researcher to interpret and to make recommendations on their behalf (Kitchin, 2000; Oliver, 1992). This is not just paternalistic but compounds the oppression experienced by PWD. How can we overcome these failures in our own report? The answer is to fundamentally reformulate the way we research disability. To do this requires adherence to a number of core principles seminally devised by Stone and Priestley (1996; cited in Kitchin, 2000). They require: 1) the adoption of a social definition of disability as the epistemological basis of research production (more on this below); 2) “the surrender of claims to objectivity through overt political commitment to the struggles of disabled people;” 3) ‘the willingness to only undertake research where it will be of practical benefit to the self-empowerment of disabled people and/or the removal of disabling barriers’ (Stone & Priestley, 1996). These principles were at the heart of our research design, and have informed our work throughout. We feel the third principle is particularly relevant in the case of our report.

Moreover, as nondisabled people we are privileged in ways that are largely invisible in our daily lives; the very fact we are in the position to write this report is a privilege in and of itself. Recognising these privileges is not just an exercise in reflexivity but a crucial task in examining ableist epistemologies (for more on this, see Scully, 2020). Our identities, be it based on gender, ethnicity, class or ability, affect the way we encounter the world and the way it encounters us, it informs what we know, how we think, and how we make sense of the social world. This is exacerbated, and is more pernicious, in the context of a capitalist system which determines who is valuable and worthy based on productive potential. With this considered, we firmly believe, as many have argued, that learning about disability requires a great deal of unlearning. It requires a fundamental change in perspective that is anti-capitalist and anti-colonial in nature, one that sees, as this report has argued, disability as a product of the social world and not as a biological category. Unlearning our implicit knowledge is a difficult task, however. In The Fire Next Time, James Baldwin wrote that "any upheaval in the universe is terrifying because it so profoundly attacks one’s own sense of one’s reality” (Baldwin, 1963, p. 17). This challenge in generating attitudinal change ‘is particularly difficult in the case of disability because of the persistent and profound ambivalence, sometimes hostility, toward anomalous bodies’ (Scully, 2020, p. 12). Difficult though it may be, this is the task at hand and it is a crucial one. Unlearning ableism, much like with racism and sexism, is the key with which empowerment, justice and equality can be achieved for PWD. In
highlighting the barriers and challenges faced by PWD in disaster settings, and thus laying out the practical implications of ableism, this report hopes to have modestly contributed to an emerging field in which more action (not just policy) is urgently needed.