



DRR DYNAMICS

INVISIBLE AGAIN:
**HYPER-MARGINALISED
GROUPS AND DISASTER
DATA**

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ABOUT DRR DYNAMICS

DRR Dynamics Ltd is a research and advocacy organisation formed in June 2014. Its primary goal is ensuring marginalised groups are better included in disaster risk reduction (DRR), disaster risk management (DRM) and humanitarian policy and practice.

Evidence repeatedly shows that groups outside of mainstream society or with limited social/ economic or educational capital (women and girls, older people, those with disabilities, ethnic minorities/ indigenous populations and LGBTQIA+ groups) are more likely to be impacted by a disaster or emergency event. Indeed, numerous recent events have shown these groups often experience higher rates of mortality, injuries or economic disruption.

The groups most marginalised within disasters often have the least input to the development of DRR policy and practice at local, national, regional and international levels. This can create a policy or programme devoid of marginalised groups representation and without proper recognition of the needs and specific requirements of these groups.

DRR Dynamics advocates that marginalised groups should be seen as agents of change who are not only able to contribute to DRR policy and practice but in turn, make it more efficient, inclusive and fair.

INTRODUCTION

Data collection, analysis and storage faces multifaceted challenges in all disaster and humanitarian contexts. But when working with or on behalf of groups that traditionally sit outside the norms of society (the marginalised or hyper-marginalised), the issues of data collection becomes even more complex.

The processes by which data collection is undertaken in disaster spaces can exacerbate the invisibility of certain groups, this is particularly the case where the data which is collected cannot be broken down into disaggregated categories. On the other hand, the lived realities of certain hyper-marginalised groups can also create challenges to their data being collected in the first place.

This paper will consider the importance of data in disaster and humanitarian contexts, with specific focus on hyper-marginalised groups. Upon examining the role of data in tracking progress towards the Sendai Framework for Disaster Risk Reduction, this paper will briefly outline the increasing shift towards more inclusive data practices and recognising intersectional vulnerabilities. The paper will proceed to explore more specifically the practical, logistical and ethical considerations of collecting the data needed to best serve these sections of society. After this examination, policy recommendations will be set out to examine how the disaster and humanitarian field can build safe and inclusive data collection processes and contribute to more equitable disaster risk reduction efforts.

For the purposes of this paper, hyper-marginalised refers to any group experiencing additional vulnerabilities because of cultural and societal attitudes & discrimination including (but not limited to) LGBTQIA+ people, first nation/ indigenous people, sex workers/ those within the informal economy, those experiencing homelessness, refugees, migrants, transient populations.

BACKGROUND

Data is critical in all aspects of disaster risk reduction (DRR) and humanitarian emergencies, insofar that incomplete or wrong information (either through collection, analysis or implementation) can lead to inappropriate or even dangerous interventions (IFRC, 2005). Data provides governments, NGO's and first responders with information on how to best mitigate and reduce the impacts of a hazard on society. Data which is collected and used effectively allows for enhanced situational awareness in disaster spaces (Homberg, 2016), and so to ensure more effective DRR, disaggregated data (data that can be separated into smaller parts for the purposes of analysing trends and providing better insights) is needed in order to identify the differentiated impacts of disasters on different communities (Green, Lysaght & Saulnier et al., 2019).

Disaggregated data is important in a number of ways, not least it can lead to the pre-disaster identification of vulnerable communities (GFDRR, 2019). Collecting specific data on hyper-marginalised groups can inform the allocation of funding and thus ensure the effectiveness of often scarce and shrinking budgets and the provision of specific aid to these groups (GFDRR, 2019). The current lack of disaggregated data (at all stages of the process) resultantly reinforces the invisibility of hyper-marginalised groups in disasters and the specific impacts they endure. This additional invisibility consequently limits the effectiveness of disaster preparedness and response, whilst also being in contradiction with the global United Nations led drive to leave no one behind.

The focus on sustainable development further highlights the importance of data, via the importance assigned to tracking DRR progress. The implementation and monitoring of the Sendai Framework for Disaster Risk Reduction (SFDRR), for example, relies on multiple data sets as recorded by the Sendai Monitoring Framework System. Ensuring systematic data collection further aligns strongly with Priority 4 of the SFDRR to enhance preparedness and effective response (Migliorini et al., 2019).

The SFDRR guiding principle 19(g) further highlights the importance of disaggregated data specifically, but in doing so limits its mention of disaggregating factors to those related to sex, age and disability, thus furthering the invisibility of hyper-marginalised groups in data collection for the purposes of the Sendai Framework goals (Sendai Framework, 2015-2030).

These sentiments of excluding hyper-marginalised characteristics from the meaning of disaggregated data within this field are similarly reflected by the Sphere Handbook, however, unlike the SFDRR, the Sphere Handbook does note that “where possible, disaggregate further by other diversity characteristics or risk factors” (Sphere, 2018). Thus indicating a recognition that further characteristics should be considered when collecting data to develop a greater understanding of vulnerabilities and risks in humanitarian settings (Sphere, 2018).

AN INCREASING SHIFT TO INCLUSIVE DATA PRACTICES & INTERSECTIONALITY

In recent years, there has been an increasing drive to promote inclusive data practices. For example, there has been an increased promotion of migrant-inclusive data by the International Organisation for Migration (IOM) through their guide on 'Migrants in Disaster Risk Reduction: Practices for inclusion (IOM, 2017) and more recently their 'Leave No Migrant Behind: The 2030 Agenda and Data Disaggregation' guide (Mosler, 2021). Similarly, the IOM has also developed Lesbian, Gay, Bisexual, Transgender, Queer, Intersex (LGBTQI) training packages to support effective assistance to LGBTQIA+ people in emergencies and have an increasing focus on inclusion through their social inclusion programming. Likewise, in 2018, Data4SDGs launched their Inclusive Data Charter to encourage actors to prioritise inclusive data practices (Data4SDGs, 2018). This Charter, in particular, has also been at the forefront of recognising the importance of intersectionality within data (albeit in a field other than humanitarian aid and disasters).

In relation to health emergencies, the World Health Organization's (WHO) Health: Emergency and Disaster Risk Management Framework (ERDM) also emphasises the critical need to take account of populations with diverse needs. In addition to setting out principles including comprehensive emergency management and taking all-hazard and risk-based approaches to disaster risk management (DRM), the WHO's Health EDRM further embodies an inclusive, people and community centred approach. This approach seeks to ensure the non-discriminatory participation of all people in the development of disaster-related policies and practices. Notably, with disadvantaged groups in mind, the Health EDRM reiterates the essential use of disaggregated data to inform, plan and evaluate disaster policies and action (WHO, 2019).

In June 2021, the Global Partnership for Sustainable Development Data launched their series 'Unpacking Intersectional Approaches to Data' which recognised the

dangerous consequences uncritical data practices can have on those most marginalised and how this can even perpetuate disadvantages and discrimination. The series stipulated that “intersectional approaches to data should be adopted by governments and organisations to improve the quality of life of people who have been compromised by intersecting inequality”, and further set out recommendations for implementing intersectional approaches to data (Inclusive Data Charter, 2021). The intersection of factors such as (but not limited to) a person’s age, gender, sexual identity, race, culture, religion, disability, socio-economic status, geographical location or migration status can result in greater disadvantages faced by some groups or individuals compared to others. In this regard, such an intersection of different identities and characteristics can create or heighten an individual’s risk in disasters (Newnham, Ho & Chan, 2018).

Despite the growth in more inclusive data collection policy, the limited meaning given to 'vulnerable groups' and the omission to specifically recognise hyper-marginalised groups, results in a failure to include such groups and individuals in data collection. Thus, resulting in their continued invisibility in overall disaster-related data.

BARRIERS TO INCLUSION

While groups considered by the authors as hyper-marginalised vary greatly and are in and of themselves not homogeneous but heterogeneous within the categories used in this paper, current research indicates some shared barriers to hyper-marginalised groups when considering inclusive data collection in humanitarian and disaster contexts.

For example, a key challenge to the collection of data of hyper-marginalised communities is a lack of international consensus on data collection processes for vulnerable groups specifically (UN ESCAP, 2013). This barrier can be exacerbated further by a social and/or political reluctance or structures that fail to recognise certain hyper-marginalised groups.

For example, hyper-marginalised groups are least likely to be identified in national census data (Green, Lysaght & Saulnier et al., 2019). Likewise, data in disasters may be compiled and analysed on the basis of procedures and definitions unique to each individual country. As such, if a certain state does not 'recognise' a hyper-marginalised group, then they may not be accurately accounted for within data. For post-disaster recovery efforts, this omission from within disaster data may result in the "rebuilding instead of reducing risks" (UN ESCAP, 2013).

Other barriers to inclusion of the hyper-marginalised, include;

- attitudes and discrimination of wider communities which are falsely held,
- barriers found within the environmental and built environment realms,
- barriers to readily access information and communication,
- institutional barriers including laws, policies and procedures of states and non-state actors and organisations can lead to direct or indirect discrimination against vulnerable groups (Sphere, 2018),
- Security concerns, particular barriers and fears of data protection which may prevent an individual from providing accurate data (WHO, 2020) and;
- the geographical movement or hard-to-reach locations of hyper-marginalised groups

The impact of these barriers on data collection of hyper-marginalised groups and individuals in disasters is largely unexplored.

PRACTICAL CHALLENGES FOR RESEARCH

There are a range of practical challenges in disaster settings that may inhibit data collection, such as restrictions on reaching remote areas, access to marginalised groups and qualified staff and researchers to undertake data collection (Benelli et al., 2012). However, in order to develop effective policy to improve equitable and inclusive DRR, a greater understanding of hyper-marginalised groups in disaster contexts is urgently needed.

But even when hyper-marginalised groups are recognised there can still be challenges and issues to consider for data collection purposes. This may include challenges arising in the sampling. For example, random sampling in disaster contexts may not capture or be representative of hyper-marginalised individuals and different sampling methods raise various biases which may further exclude hyper-marginalised groups (Newnham, Ho & Chan, 2018).

Likewise, the recruitment of individuals for research purposes raises a range of challenges. As will be discussed, hyper-marginalised individuals may have mistrust in authorities or hold well-founded fears of being mistreated or exploited. Such challenges are made more difficult in combination with difficulties in physically reaching geographically dispersed groups (migrant populations, those experiencing homeless etc) and overcoming the dangers of self-identifying in environments where a certain identity or status is illegal, faces stigma and/or discrimination (Newnham, Ho & Chan, 2018)

To examine the practical, logistical and ethical considerations of data collection for different hyper-marginalised groups, this next section will specifically consider those experiencing extreme poverty; those working in the informal economy (including those working as sex workers); individuals and communities identifying as LGBTQIA+, those experiencing homelessness; refugees, asylum seekers and migrants and transient populations.

Those experiencing extreme poverty

Poverty has often been cited as the single biggest hurdle to overcome when reducing the risks of disasters (Chmutina et al, 2021). Disasters interrupt normal economic function within the disaster location, often removing the ability to generate income for many within the affected society (Groeschl & Noy, 2020). This reduction of normal economic activity is particularly pronounced within communities already experiencing extreme poverty and hardship. Indeed, the circular nature of “poverty creates disaster risk, disasters create poverty” is often cited as a major challenge to overcome during disaster risk reduction activities (Tandi & Mawere, 2018).

One of the major challenges of this is the role of data in understanding the nature of poverty and its impacts on preparedness, response and recovery during disaster or crisis settings.

Those experiencing extreme poverty often have a number of structural and societal barriers in current data recognition and collection techniques, including (but not limited to);

- The individuals within this hyper-marginalised group are often largely invisible. Their intersecting nature with the groups to be discussed below mean that collecting and analysing data from this section of society experiences the a combination of challenges. Such as, a lack of trust of authorities, societal discrimination, and status within the country can be problematic (based on residency, profession etc).
- Time taken to engage with this community is often highly valuable to those experiencing extreme poverty. This time answering questions and/ or surveys is time taken away from earning money. As such, engagement with this group is often complimented with a financial incentive.

Sex workers

During disasters or other periods of emergency, commercial sex workers face disproportionate risks and exposure. For example, barriers faced in accessing forms of contraception may increase the health risks faced by individuals for providing their services (Djello & Quevedo-Gomez, 2015). Further, the immediate consequences of a disaster may result in restrictions on movement (as we witnessed during the COVID-19 pandemic), the closure of businesses and economic activities which may disproportionately affect hyper-marginalised groups, such as commercial sex workers, more so than other groups as they have little legal recognition for state-backed support (Mulvihill, 2020). The same goes for informal (or grey-economy) workers, as highlighted by the UNDP reflecting upon previous epidemic outbreaks, “general informal workers without social protection or any kind of insurance, are disproportionately affected – both by the disease and by government responses to it” (UNDP, 2020).

Government-imposed executive orders in response to disasters, such as those to the COVID-19 pandemic, can also have disproportionate impacts on the livelihoods of sex workers. For example, nighttime curfews imposed in Puerto Rico in March 2020 resulted in nighttime outreach work to sex workers being completely eliminated. Due to this policy, which if broken placed an individual at risk of a \$5,000 fine or up to 6 months in prison, an additional layer of criminality was added to sex workers livelihoods (Melin, Quiñones & Rodríguez-Díaz, 2021). In this case, reactionary action to a disaster by authorities can disproportionately impact hyper-marginalised groups such as sex workers.

In addition to being a criminal offence in some environments, commercial sex work can also be highly stigmatised and culturally sensitive (Gbagbo, 2020). Such stigmas toward sex workers can be perpetuated further by fears, misinformation, and negative societal attitudes surrounding HIV/AIDS (Mastin et al., 2016). This can make collecting data on commercial sex workers even more complex as, in times of disasters, their lack of safeguards or protections is exacerbated due to existing unfriendly political and social climates surrounding the nature of their work.

Similarly to other hyper-marginalised groups, discrepant views on the definitions of commercial sex workers in the first place, as well as unreliable existing data sources, result in a difficulty to ascertain the number of sex workers in many countries in the first place (Fuber et al., 2002; Kaufman et al., 2016).

LGBTQIA+ people

Currently, data pertaining to the impact of disasters is “overwhelming focused in the binary-gender split of men and women” (Benelli et al 2012) and “traditional” heteronormative ideals of relationships (Rushton et al, 2019). And so, data does not capture those with diverse sexual orientation, gender identity or expression. Likewise, many countries still criminalise activities related to LGBTQIA+ individuals. Thus, a key barrier to inclusion within data is the fear of being ‘outed’ or a person becoming victim to “vigilante attacks due to raising their visibility as LGBT” (Human Dignity Trust, 2019). Understandably, there remains to be a lack of trust by LGBTQIA+ communities towards law enforcement and other authorities, and this lack of trust can be a key barrier to accurate data collection in disaster contexts.

As highlighted by Fontanez, trust towards emergency services, in particular, can waver due to negative past interactions with the authorities, as well as discrimination held by the local communities and community leaders (Fontanez 2019; Briones-Robinson et al., 2016). Similarly, aid providers in the past, have expressed fears and reservations about conducting LGBTQIA+ friendly services in certain LGBTQIA+ unfriendly country settings (Parkinson et al, 2021). Such concerns held by aid providers link strongly to fears of jeopardising the ‘do no harm’ principle found within humanitarian aid. These ethical considerations are exacerbated further by the question of how best to store and collect data safely and the fears held by LGBTQIA+ people that such data may be used to persecute them later on.

Refugees, asylum seekers & migrants

Refugees and migrants as a group are widely heterogeneous with wide-ranging sub-populations and distinctions (WHO, 2020). This is vital to recognise, as each sub-group (for example international students, unaccompanied minors, irregular migrants) all come with varying vulnerabilities, capacities and specific considerations.

Refugees, asylum seekers & migrants (cont.)

Collecting data to better provide for and represent refugees and migrants in disasters can be especially difficult due to challenges in accessing sub-groups, mistrust of authorities, and language barriers. This is especially frequent in sudden onset disasters, which allow emergency managers little time to procure translation services (WHO, 2020).

The IOM details how migrants specifically are

- “virtually invisible to disaster response agencies in the country because of the remote location of their residences and workplaces; fears linked with their immigration status if they are undocumented; substandard housing conditions; a lack of access to private means of transportation; a lack of knowledge of their rights, including their right to receive emergency assistance; and fear of harassment or being targeted by local agencies, service providers, contractors and employers”. (IOM, 2017)

When disaster strikes, migrants may also face unique challenges in terms of being viewed suspiciously, with discriminatory views held in host communities (IOM 2017), in so far that some migrants may consciously avoid interaction with social and public agencies (Centre for Disease Control and Prevention, 2010).

Further, migrants often live in informal settlements (which are often considered “illegal settlements” by the authorities within the host country) and hazard-prone areas which results in them being the first and worst affected by disasters, particularly during climate-related disasters (Mosler, 2021). As identified by the IOM, “the number of projected earthquake casualties in Turkey increased from 1 to 26 per cent when accounting for Syrian refugees” (IOM and Council of Europe, 2017).

Similarly to other hyper-marginalised groups, the lack of uniform international consensus or definition of what constitutes “a migrant” can have implications for who is recognised as a migrant during data collection (WHO, 2020).

Disaggregated data, which should include migrants (as per the Sendai Framework) is essential for policymakers and DRR efforts. Data around the migratory status of individuals and communities can inform the need for translation and more effective dissemination of early warning messages and communication which is critical to saving lives from the onset of a disaster (Mosler, 2021).

Transient Populations

Transient communities such as Gypsy, Roma and Traveller communities (GRT), face a range of barriers and challenges to inclusion within mainstream society as they can often face rejection, discrimination and racism (Equality and Human Rights Commission, 2016). From a research and data collection perspective, transient communities face multiple barriers, including language and literacy, as well as barriers to recruitment for data collection in the first place. Such barriers can include holding a mistrust of the authorities, fears of harm and cultural beliefs (Condon et al., 2019). The lack of systematic and routine data collection of these communities means that the impacts of disasters on these groups specifically is largely hidden. This is particularly problematic as transient communities are recognised as facing extreme health inequalities, even in times of non-disaster, which is a factor likely to be exacerbated in times of disaster (McFadden et al., 2018).

Grey economy/ Informal sector workers

The informal economy, grey economy or shadow economy is a part of a country's economy that isn't taxed, and as such, isn't recognised within official gross domestic product (GDP) calculations (Bonet et al, 2019). The size of a country's informal economy is often unknown because of the lack of data on the topic, but economists within the European Union have suggested the informal economy within those countries in 2014 was somewhere between 3% and 7% of total GDP (OCCRP, 2014). It is often suggested that the informal economy is a much larger share of the GDP in less economically developed countries and those countries within the Global South (Skinner & Watson, 2018).

Within the discussion of hyper-marginalisation and disasters, the informal economy plays a considerable role. Indeed, many of the groups discussed previously are key contributors to this section of the economic output of a country (Bustamante, 2018).

Grey economy/ Informal sector workers (cont.)

Sex workers, migrants and refugees, people experiencing homelessness have all been shown to engage with the informal economy on a daily basis (Schwettmann, 2020). This number only increases in the aftermath of a disaster, when opportunities in the official economy are reduced (Schwettmann, 2020).

The role of gender inequalities is also rife within the informal economy, with research often showing women and girls most frequently work within this sector (Joseph et al, 2020). Indeed, if you consider unpaid domestic and child-rearing work as part of the informal economy, then it's women and girls who make up the majority of the sector (Joseph et al, 2020). However, given the lack of official and verified data on the topic, there remains a gap in policy development regarding how to engage with and support those who rely on the informal economy after a disaster.

Homeless individuals and populations

People experiencing homelessness (PEH) are faced with a range of vulnerabilities in disasters, such as shelter concerns, financial constraints, lack of official recognition, limited material resources, health concerns, violence and substance abuse (Morris, 2020). These challenges can mean collecting data on people who are experiencing homelessness outside of a disaster setting poses its own challenges, and this should be considered when seeking inclusive data practises within disaster spaces. For example, if measurements of homelessness are based on those in homeless shelters specifically, this excludes 'hidden homelessness' whereby people who have been made homeless use different services or means i.e those made homeless due to domestic violence who then use domestic violence services instead of homeless services (Bretherton, 2017). Indeed, the very definition of what constitutes "homelessness" can impact the level of assistance and support members of the hyper-marginalised communities can rely on (Wexler & Smith, 2015)

Homeless individuals and populations (cont.)

Importantly, PEH is recognised as not being a homogenous group, but rather intersectional social identities result in vastly differentiated impacts and experiences of disasters (Vickery, 2018). However, during a disaster, as with other marginalised groups, PEH may hold mistrust or scepticism for police, or authorities who are providing aid, for whom they may have had previous negative experiences of punitive action towards them (EKU, 2017). Due to fears held towards authorities, PEH who are undocumented or those with ongoing criminal activities or records may be particularly hesitant to allow data capture or to engage in disaster activities (Morris, 2020). Another practical challenge to data collection of PEH during disasters is access, as during disasters there is often a closure of services upon which such individuals may be reliant, (Morris, 2020). For data collection purposes, this can make accessing PEH more difficult.

ETHICAL CONSIDERATIONS

In this next section, we will briefly examine critical ethical considerations for the engagement of hyper-marginalised groups in disaster data collection.

As set out by the Sphere Handbook “data disaggregation must be balanced with safety and protection concerns around collecting sensitive data and the data minimisation principle.” (Sphere, 2018). This measure is key when collecting data on hyper-marginalised groups as such inclusive data practices raise a range of ethical considerations that need to be factored in for the safe and effective collection of data of hyper-marginalised groups in disaster and humanitarian contexts.

A recent 2020 bioethics guide by the Nuffield Council highlights how;

- “it is vitally important to be aware of, and sensitive to, the historical record (for example, histories of colonisation, and narratives of paternalistic imperialism as well as histories of oppression, marginalisation, and conflict within affected communities) and to take active steps to address distrust and concerns arising in that context.”

The guide further reiterates that there is an ethical imperative to find ways of engaging with marginalised groups (Nuffield Council, 2020).

In relation to ethical principles, it is notable to consider that the inclusion of hyper-marginalised groups allows for social justice and promotes the identification and fair treatment of hyper-marginalised groups in disaster contexts (Ferreira, Buttell & Ferreria, 2015). Such concepts of social justice align with the global goals to leave no one behind, a call echoed across the disaster field through the reiteration to take an ‘all of society’ approach to DRR. However, despite these good intentions, research undertaken around disaster settings may present distinctive ethical concerns compared to research conducted in non-crisis settings (Tansey, Anderson & Boulanger et al., 2017).

And so, it is key that ethical considerations be embedded from the very initial concept and design for research processes when seeking data on hyper-marginalised groups in disasters (Mena & Hilhorst 2021). This is particularly vital as the fast-changing and evolving environments that accompany disasters may result in “hastily written” and acted upon ethical protocols for research that do not adequately protect marginalised or hyper-marginalised groups (Tansey, Anderson & Boulanger et al., 2017).

The vulnerability and exposure of those being interviewed or used as data points are widely recognised as an overarching concern for disaster research ethics (Tansey, Anderson & Boulanger et al., 2017) as research participants are likely to have heightened vulnerability due to destabilisation and destruction following a disaster (Macklin, 2014). Linking to this, informed consent raises further ethical issues in disaster settings where participants are more vulnerable than they normally would be. Similarly, using financial incentives in disaster spaces also raises particular ethical issues given the heightened vulnerability of participants (Condon et al., 2019). In the absence of policy on the collection of data for hyper-marginalised groups specifically in disaster contexts, many lessons can be learnt and transferred from research into health emergencies. For example the, Médecins Sans Frontières research ethics framework, 2019, and likewise ethical guidelines established for disaster settings specifically (Mezinska, Kakuk & Mijaljica et al., 2016).

Furthermore, capturing and storing data digitally raises ethical concerns regarding data protection and security. The increased affordability of mobile services and the expansion of digital inclusion presents opportunities to empower marginalised communities. However, there is a prospect of doing digital harm. This being a negative impact on an individual, group or organisation due to the disclosure or corruption of sensitive data or when said data becomes unavailable when needed (Homberg, 2016). This prospect becomes a critical consideration when engaging with hyper-marginalised groups in disasters. To undertake data collection on marginalised groups there must be confidentiality and data security, particularly in austere environments (Tansey, Anderson & Boulanger et al., 2017).

The widespread use of data collection via mobile phones is encouraged by some given its ability to allow anonymous and de-identifiable data collection, as well as the widespread possession of mobile phones and the insecure nature of keeping data in hard copy in the field.

Despite this, the use of data collection via mobile phones is equally accompanied by warnings and expectations for researchers to ensure participant confidentiality and ensuring data security.

In addition, as highlighted by a 2013 UN ESCAP report, each phase of a disaster presents new challenges to information management (UN ESCAP, 2013). Likewise, Oxfam also warns that the exclusion of those most marginalised may in fact be exacerbated by virtue of using mobile phones for data collection. Thus, the use of mobile phones during disasters may require a certain technological skill set or language to complete and this in itself may not be desirable. Even when multiple languages are provided for via digital platforms, issues of translation arise. For example, surveys written in multiple languages may create issues faced by data collectors including the risk of insights being lost in translation (Oxfam, 2017). While the utility of using mobile phones for data collection is likely to vary between different disaster settings, there remains to be a gap in policy that sets out the safe, and importantly ethical, engagement of hyper-marginalised communities in data collection for the purposes of effective and inclusive DRR.

Often, hyper-marginalised communities represent a small portion of the overall population, however, there is currently limited policy explicitly recognising the need for, and safe processes to, collect data on hyper-marginalised communities to ensure effective and equitable disaster response. In response to this, in 2020, a large group of scholars signed a manifesto called *Power, Prestige and Forgotten Values: A Disaster Studies Manifesto*, which advocated for inclusive DRR research and the re-thinking of research agendas, methods and allocation of resources (Gaillard, 2019). The aims of this manifesto are in line with other concerns that have been raised in disaster spaces such as the need to ensure research in disaster spaces does not perpetuate power imbalances, as well as cause other harms such as re-traumatization or research fatigue (Cronin-Furnman & Lake, 2018; Patel et al, 2020).

RECOMMENDATIONS

To uphold the underlying humanitarian principles that drive humanitarian response as well as the global commitment to leave no one behind, substantive and context-specific frameworks need to set out how data can safely and securely capture all of society so as to inform more effective disaster risk management. There are some promising developments in pursuing more inclusive research protocols which will hopefully result in the better visibility of hyper-marginalised groups in disaster data. However, the current lack of policy recognition of hyper-marginalised groups in disasters means their invisibility in data is exacerbating their vulnerabilities in disasters.

The increased frequency of disasters worldwide is leading to a corresponding increase in disaster research involving human subjects. To support this, some researchers have suggested the development of a universal code of ethics when conducting disaster research with vulnerable populations (Ferreira, Buttell & Ferreria, 2015) while others consider the existing frameworks and guidance policies on ethical consideration for research to be effectively transferable to disaster studies.

After examining the challenges and ethical considerations of hyper-marginalised groups in disasters for the purposes of data collection, the following recommendations are made:

Recommendation 1

Data collection in disaster or crisis situations must recognise and include the characteristics of hyper-marginalised groups, this is especially important when considering factors for collection of data that can be disaggregated.

RECOMMENDATIONS (CONT.)

Recommendation 2

The development, agreement and widespread implementation of a standardised data collection process on vulnerable groups is needed. This should include recognition of the importance of disaggregated data and also establish and agree on indicators related to vulnerability and exposure for the hyper marginalised.

Recommendation 3

Promote and advocate for greater investment in research around the impact of disasters on hyper-marginalised groups and ensure inclusive approaches are taken to DRR programming and implementation

Recommendation 4

The development, implementation and monitoring of inclusive data practices should never blame those who are marginalised (e.g. by referring to 'self-exclusion' and referring to issues of self-perception and lack of confidence as factors that lead people to exclude themselves). Policymakers should focus on researching why so-called 'self-exclusion' has occurred and then building responses which tackle that specifically.

RECOMMENDATIONS (CONT.)

Recommendation 5

Policymakers should aim to ensure collaboration with existing community networks and structures at the earliest opportunity in the development of any policy related to marginalised and hyper-marginalised groups. There should be recognition at the outset that many organisations and agencies already have extensive knowledge about the needs of various hyper-marginalised groups. And so, direct service providers may be best positioned to engage hyper-marginalised communities for the purposes of collecting data in disasters.

Recommendation 6

To ensure the needs, rights and safety of hyper-marginalised groups are recognised, those institutions collecting data should ensure all volunteers and employees are trained on how best to communicate and engage ethically with hyper-marginalised groups. This should include flexibility to change collection procedures and locations if needed for the safety and security of those communities being engaged.

RECOMMENDATIONS (CONT.)

Recommendation 7

Policymakers should recognise the limits of a purely quantitative data collection methodology, especially when collecting data involving specific sensitivities and consider the role and utility of including complementing quantitative data with qualitative analyses.

Recommendation 8

Frameworks & processes for data collection should consider implementing participatory action research to collect data on hyper-marginalised groups so that participants engage in data collection as co-researchers thus challenging traditional knowledge and power relationships.

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