



# Sex, age (and more) *still* matter

**Data collection, analysis, and use  
in humanitarian practice**

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# Contents

- Foreword – CARE ..... 4
- Foreword – UN Women..... 5
- Acronyms ..... 6
- Executive Summary and Key Findings..... 7
  
- CHAPTER 1**
- Introduction, Methods, and Overview ..... 10**
  - Study Methods ..... 16
  - Report Overview ..... 16
  
- CHAPTER 2**
- Sex and Gender Analysis, Diverse SOGIESC, Age, Disability, and Intersectional Analysis and Use in Humanitarian Practice ..... 17**
  - Sex Specific Data and Gender Analysis ..... 17
  - Breakdown of the use of SADD in clusters across 22 country Humanitarian Needs Overviews..... 21
  - Diverse Sexual Orientation, Gender Identity and Expression, and Sex Characteristics ..... 26
  - Age ..... 29
  - Disability ..... 34
  - Intersectionality ..... 41
  - Data Management, Analysis, and Use..... 45
  - Conclusion..... 48
  
- CHAPTER 3**
- Case Studies ..... 49**
  - The Way Forward..... 54
  
- CHAPTER 4**
- Conclusion and Recommendations ..... 56**
  - Recommendations for humanitarian donors and actors ..... 58
  
- References ..... 59**
- Endnotes..... 65**

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# Foreword – CARE

Data has the power to transform how we see the world. Through big data collection and analysis, we are increasingly able to monitor health, poverty, education, gender equality and climate change on a scale never seen.

For organisations such as CARE, data provide a critical window through which we monitor the reach, impact and operational effectiveness of our work and programs. Yet while we have seen rapid advancement in the last 10 years in big data collection and analysis around the world; the humanitarian sector has remained painfully slow in keeping up with this trend.

Ten years ago, academics from the Feinstein International Center at Tufts University with the support of the United Nations Office for the Coordination of Humanitarian Affairs and CARE International, shone a spotlight on the paucity of collection and analysis of sex- and age-disaggregated data (SADD) in a landmark study “Sex and Age Matter”. The study made a powerful case on the need for good data to aid decision-making and programming in humanitarian response, and how if such data is not effectively disaggregated to show impact across different groups of people, then it is difficult to know if the needs of those groups have been met.

Led by the Feinstein International Center, and developed in partnership with CARE and UN Women, this current report analyses progress made across the sector in terms of the collection and use of disaggregated data in the 10 years since.

The report notes that some improvements have been made across the sector. For example, at CARE, our Rapid Gender Analysis tool, used in over 70 countries affected by crisis, is one way we collect, analyse and use SADD as a means of informing our humanitarian programming. We are also seeing improvements across the sector in the use of age data and greater effort to consider and incorporate disability data collection and analysis.

Despite this, progress remains piecemeal across the broader humanitarian community, and this important report makes clear that persistent gaps in our knowledge exist. For example, when it comes to sexual orientation, gender identity, gender expression and sex characteristics data collection, the community remains hesitant, and it is rare to see any intersectional analysis of disaggregated data. Even in the best cases of collecting, analysing and using SADD, there is very little documentation of how this information was used to inform and improve programming, or to ensure that we are accountable to the communities we serve.

In the foreword to the landmark report 10 years ago it was noted how “the humanitarian community has not invested enough in collecting and using SADD to inform our programming”. A decade later, in the foreword to this report, this statement disappointingly still rings true.

We can do better in how we collect, use, and analyse data in ways that advance the dignity and rights of the people we serve. This report provides a clear pathway to address these persistent data gaps and ensure the most marginalized are not just made more visible, but are also better equipped with the tools, resources, and agency they need to lead humanitarian decision-making. Only in doing so can we ensure that we deliver accountable, transparent, and high-quality assistance that genuinely meets the needs of all people, in all their diversity.

**Sofia Sprechmann Sineiro**  
Secretary-General  
CARE International

# Foreword – UN Women

This report comes as we raise the alert on global gender equality backsliding and on the need for intensified focus on reversing that trend, for which accurate data is essential. Our latest report on progress in attaining the Sustainable Development Goals and especially SDG 5, estimates that at current rates, it will take close to 300 years to achieve full gender equality.<sup>1</sup> Only 47 per cent of the data required to track progress on SDG 5 is currently available. Disaggregated data and gender analysis – as outlined in this report and the annual Gender Accountability Framework (GAF) report – are essential for us to see which populations are most affected in crisis settings and whether or not they have access to assistance. In addition to supporting an informed perspective on gender-related issues, when we have information on women’s age, disability and diverse SOGIESC<sup>2</sup>, that intersection helps us to more effectively identify and reach the populations most in need.

This year sees the fourth annual publication of the GAF report, developed by UN Women in its role as the Gender Desk of the Inter-Agency Standing Committee (IASC) Gender Reference Group. UN Women is now a full member of the IASC, which is an important recognition of the humanitarian system’s increased focus on gender and accountability to affected populations. UN Women will continue to work closely with CARE and all members of the IASC to strengthen the mainstreaming and prioritization of gender and intersectionality in humanitarian action.

Good progress has been made in improving the use of gender analysis and sex- and age-disaggregated data (SADD) in the field-planning phases and the response plans. In 2020, for the first time since the GAF report analysis began in 2018, more than half of the Humanitarian Needs Overviews demonstrated the use of SADD and gender analysis. Over 90 per cent of the Humanitarian Response Plans reviewed included provisions for sexual and reproductive health and for mitigation and response to gender-based violence. However, there is much still to improve: to act on the GAF recommendations, which remain largely unchanged year after year, and to accelerate the pace of reaching new, more ambitious goals.

The *Sex, Age (and More) Still Matter* report outlines the challenges in the implementation of recommendations across the field and the need at all levels to confront the continued lack of accountability that perpetuates heightened risks of discrimination, inequality, and gender-based violence for women and girls in crisis contexts. The additional implications of the intersectionality of sex, age, disability and diverse SOGIESC must also be examined through adequate collection, analysis, and use of disaggregated data in order to be fully understood. Only then will the full inclusion of women and girls in all their diversity, and at all levels of humanitarian action, be possible.

## **Sima Bahous**

UN Women Executive Director and United Nations  
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<sup>1</sup> Progress on the Sustainable Development Goals: The gender snapshot 2022. <https://www.unwomen.org/en/digital-library/publications/2022/09/progress-on-the-sustainable-development-goals-the-gender-snapshot-2022>.

<sup>2</sup> SOGIESC: sexual orientation, gender identity, gender expression and sex characteristics



# Acronyms

<b>DFAT</b>	Department of Foreign Affairs and Trade
<b>DFID</b>	Department of International Development, United Kingdom
<b>DG ECHO</b>	Directorate-General for European Civil Protection and Humanitarian Aid Operations
<b>EU</b>	European Union
<b>GAGE</b>	Gender & Adolescence: Global Evidence
<b>GAM</b>	Gender with Age Marker
<b>GBV</b>	gender-based violence
<b>GBV IMS</b>	gender-based violence information management system
<b>GCA</b>	government-controlled areas
<b>GENCAP</b>	Gender Standby Capacity Project
<b>GIHA</b>	The Gender in Humanitarian Action
<b>HNO</b>	Humanitarian Needs Overview
<b>HQ</b>	Headquarters (HQ)
<b>HRP</b>	Humanitarian Response Plan
<b>IASC</b>	Inter-Agency Standing Committee
<b>INGO</b>	international non-governmental organization
<b>IRC</b>	International Rescue Committee
<b>LGBT(Q)</b>	lesbian, gay, bisexual, and trans (queer)
<b>MEL</b>	monitoring, evaluation, and learning
<b>NGCA</b>	non-government-controlled areas
<b>NGO</b>	non-governmental organization
<b>OCHA</b>	Office for the Coordination of Humanitarian Affairs
<b>ODI</b>	Overseas Development Institute
<b>RGA</b>	Rapid Gender Analysis
<b>SADD</b>	sex- and age-disaggregated data
<b>SADDD</b>	sex-, age-, and disability-disaggregated data
<b>SDG</b>	Sustainable Development Goal
<b>SMART</b>	Standardized Monitoring and Assessment of Relief and Transitions
<b>SOGIESC</b>	sexual orientation, gender identity and expression, and sex characteristics
<b>UN</b>	United Nations
<b>UNFPA</b>	United Nations Population Fund
<b>UNHCR</b>	United Nations High Commissioner for Refugees
<b>UNICEF</b>	United Nations Children's Fund
<b>UNOCHA</b>	United Nations Office for the Coordination of Humanitarian Affairs
<b>UN Women</b>	United Nations Entity for Gender Equality and the Empowerment of Women
<b>USAID</b>	United States Agency for International Development
<b>WHO</b>	World Health Organization
<b>YLD</b>	years lived with disability



## Executive Summary and Key Findings

### Progress has been made but more is needed:

**1. The gender myth:** Nearly everyone in the humanitarian industry that we interviewed has the strong perception that their agencies are regularly and systematically collecting and using sex-disaggregated data and gender analysis to inform their humanitarian planning and programming. Yet the documentation and evidence to support these claims is very often poor and, in most cases, non-existent. This mistaken perception is very problematic as it gives the impression that “the job is done,” when in fact research from 2020 finds that approximately half of humanitarian needs overviews in the last few years have not used any sex-disaggregated data.<sup>1</sup>

**2. A long way to go:** Over the past 10 years the humanitarian sector has made some progress regarding collecting sex-disaggregated data and using gender analysis to make sense of it, but the 2022 Gender Accountability Framework report shows in detail how there is still a great deal that remains to be done.<sup>2</sup> We are getting better with age data and are starting to consider and incorporate disability data collection and analysis. We remain hesitant around how to consider diverse sexual orientation, gender identity and expression, and sex characteristics (SOGIESC) in data collection. Overall, we rarely incorporate intersectional analysis of disaggregated data. Even in the best cases of collecting, analyzing, and using sex-disaggregated data, there is extremely little documentation of how this information was used to inform and improve programming. Accountability mechanisms are notably lacking and where they exist lack enforcement.

**3. Women remain marginalized in decision making:** Despite constant advocacy by women’s and girls’ rights advocates, and profiling of the situation of women and girls in humanitarian crises, they are not present in humanitarian decision making, their rights and priorities in humanitarian response remain underfunded, and advocates still struggle for humanitarian funding to be allocated for them. Yes, we do collect more sex- and age- disaggregated data (SADD), but we don’t necessarily use it and even when we do outcomes are rarely documented. Yes, we do consult women and girls and different groups, but their input too often does not meaningfully inform decisions, programs, or policies.

**4. Accountability should take center stage.** To make the progress needed in collecting and using SADD, disability, and SOGIESC data at all levels of humanitarian response, robust accountability mechanisms must be prioritized and put in place. Existing gender accountability frameworks, such as the Inter-Agency Standing Committee (IASC) 2017 Gender Equality and the Empowerment of Women and Girls in Humanitarian Action Policy, should be enforced.

**5. Impartiality requires disaggregated data:** Impartiality means that humanitarian aid must be provided solely based on need and in proportion to need. With humanitarian funding unable to meet the current needs, investment in disaggregated data analysis and use is critical to implement evidence-based and impartial programming that targets and addresses the needs of the most vulnerable.



Without an investment in relevant data disaggregation and in tools like Rapid Gender Analysis, critical at-risk populations are too often made invisible, and their specific humanitarian needs not addressed.

**6. Sex and age are no longer sufficient:** The humanitarian industry is still not where it needs to be in terms of collecting and using SADD and gender analysis. A more serious and concerted effort is needed. Investment is needed to expand the availability of tools like Rapid Gender Analysis. In addition, it is time to include disability in data collection and analysis, carry out more granular age disaggregation to capture the older persons and other age groups with specific needs, incorporate diverse SOGIESC populations whenever possible, and utilize intersectional analysis across all sectors given the compounding role of identities, capacities, and vulnerabilities. Sex, age, and disability should be variables to disaggregate data on and variables that require further disaggregation themselves.

**7. Gender is not a catch-all for inclusion programming:** Organizational needs have far exceeded the capacity for (over-worked and under-resourced) gender specialists to manage on their own. The humanitarian and development sectors need to invest in, hire, and train more robust and inclusive teams and dedicated leads to manage data collection, analysis, and programming for a variety of intersectional identities. The entire humanitarian, development, and peacebuilding career pipeline, including academia, needs to address the requirement for more inclusive specialties.

**8. We need to better coordinate, share, and use existing data:** Despite progress made in the collection of disaggregated data and the existence of multiple guidelines, a significant gap remains in the use of data to improve program implementation. To improve accountability to participants, investments should be made in increased coordination of data collection, greater sharing of existing data through investment in data dashboards, and more emphasis on secondary data analysis. The greatest emphasis in guidelines, mandates, and funding should be on data use. When disaggregated data are collected and used, funding and time need to be set aside for better documentation of how the disaggregated data affected programming and associated impact on the population for sharing of best practices, effective program examples, and lessons learned.

**9. Additional requirements on data disaggregation need to be complemented with appropriate funding support:** Increasingly donors are asking for more disaggregated data collection and analysis due to the requirements for reporting progress towards the Sustainable Development Goals (SDGs) and shifts towards greater inclusivity. These developments need to be supplemented with appropriate funding for staff, trainings, data management systems and leads, analysis, documentation of data use and impact, and experts with the appropriate knowhow. Supporting data dissemination, data sharing, data dashboards, greater coordination, and key lessons learned is a valuable way for donors and humanitarian organizations to share information across agencies and sectors to develop additional best practices for disaggregated data use and improved collective learning.



**10. Data responsibility in humanitarian action requires the safe, ethical, and effective management of personal and non-personal data for operational response.** Data responsibility is a critical issue for the humanitarian system to address and the stakes are high. Ensuring we ‘do no harm’ while maximizing the benefits of data requires collective action that extends across all levels of the humanitarian system. Humanitarians must be careful when handling data to avoid placing already vulnerable individuals and communities at further risk. This is especially important in contexts where the urgency of humanitarian needs drives pressure for fast (and sometimes untested) data solutions, and where the politicization of data can have more extreme consequences for people.

**11. More inclusive data collection, analysis and humanitarian programming is needed to meet the humanitarian community’s commitment to the localization agenda.** Humanitarian agencies need to work with national expertise, specialists, and the affected communities, in the initial stages of designing the data collection instruments all the way through reporting back and validating findings, to make sure the appropriate data are being collected in safe and ethical way. This approach is particularly critical for engagement with women and girls, older women and people experiencing disabilities, and/or diverse SOGIESC populations in humanitarian crisis. Working with civil society or local non-governmental organizations (NGOs) that know how to best work with these groups in a given context is critical for their meaningful inclusion in benefiting from humanitarian assistance.





## CHAPTER 1 Introduction, Methods, and Overview

At the time of this report, the world is experiencing multiple overlapping emergencies, including the COVID-19 pandemic, war in Ukraine, unprecedented food insecurity [or hunger] in Yemen, Somalia, Ethiopia, Afghanistan, and Nigeria, climate change severe weather events, climate-driven migration, and a rise in disability due to a growing population of older persons and conflict. Humanitarian need is at an all-time high.

The United Nations (UN) humanitarian request for 2022 was US \$41 billion to help 183 million people across 63 countries, double the amount requested in 2019 and more than triple the amount requested in 2015.<sup>3</sup> At the same time, global humanitarian funding has failed to keep up, with only about half of the requirements met in 2021.<sup>4</sup> Efficiency in targeting, program impact, and the humanitarian principle of impartiality—that aid is provided solely on the basis of need and in proportion to need—is now more important than ever.

Impartiality is not possible without an evidence-based approach that aims to collect, analyze, and use disaggregated data. Without an emphasis on disaggregated data, we risk discriminating against “invisible” populations and providing assistance that is not needs-based.

The goal of this report is to identify where the humanitarian community is with respect to the collection, analysis, and use of disaggregated data, with a specific focus on sex,

age, disability, and diverse SOGIESC data, and gender and intersectional analysis. We discuss where progress has been made in the past decade as well as highlight the remaining gaps in collecting, analyzing, and using disaggregated and intersectional data. The aim of this report is to evaluate the progress in and emphasize the need for the collection, analysis, and use of disaggregated data that allows practitioners and key stakeholders to make those assessments in a context and crisis-specific manner. The report draws on a combination of literature, key informant interviews using snowball sampling, and a workshop and Delphi panel with key humanitarian actors.

The humanitarian community has made progress since the first *Sex and Age Matter* report was published in 2011. However, progress has been uneven. Improvement is most notable around collecting and using sex-disaggregated data to inform a gender analysis in programming, with the development of gender markers, easy-to-use toolkits, and guidelines that are widely available across the humanitarian space. Today, overwhelmingly, the leading national, international, and intergovernmental donors to major humanitarian agencies *require* humanitarian agencies to collect and use sex-disaggregated data and carry out gender analysis in their work with those receiving aid. However, what is required and what is occurring among humanitarian agencies are not the same thing. Most notably, in 2020, approximately half of Humanitarian Needs Overviews (HNO),



Humanitarian Response Plans (HRP) failed to contain or consider any sex-disaggregated data or gender analysis.<sup>5</sup>

The inconsistent and limited consideration for sex-disaggregated data and gender analysis occurs in the context of increased vulnerability. It is well documented that conflict heightens and exacerbates pre-existing patterns and norms of gender discrimination, inequality, and risk of potential violence. In particular, risks of sexual and gender-based violence (SGBV) against girls, women, and individuals with diverse sexual orientation, gender identity and expression, and sex characteristics (SOGIESC)<sup>6</sup> in conflict and post-conflict societies are amplified due to the breakdown in the rule of law, the increase in small arms, and the use of sexual violence as a tactic of war. Women and girls are the predominant individuals at risk of sexual violence, but men and boys also face increased risks of SGBV especially when they are detained. In addition to the increased normalization of violence and SGBV in conflict and post-conflict societies, women and girls also face additional obstacles to access essential services particularly those related to healthcare and sexual and reproductive justice. Instability can have a disproportionate effect on girls accessing education due to fear of attack, increased caregiving responsibilities, and the risk of trafficking.<sup>7</sup>

However, women and girls should not be seen exclusively as victims of instability. Women and girls historically and today have been integral participants to the peace and reconciliation process, though their meaningful participation in formal peace processes is often stymied by parties to the conflict. Post-conflict societies can be viewed as a transformational opportunity for society to have more equitable women's rights and increased gender equality.<sup>8</sup> However, the evidence in this report around the full inclusion of women and girls in the decision-making process has been minimal.

Collection of age-disaggregated data has become more common, yet importantly it is neither consistently analyzed nor used for program adaptation, with the notable exception of the child nutrition and education sectors. Older persons, and especially older women, are a particularly invisible population, one that is usually lost in aggregation when analysis is conducted.

Furthermore, there remains a significant gap in the collection, analysis, and use of disability-disaggregated data.

However, throughout the literature review and interview process, it was clear that most humanitarian agencies, or at least specific departments within those agencies, are starting to think about how to make collection, analysis, and use of disability-disaggregated data a component of their monitoring and evaluation process and programs. More so, given the progress of key donors, non-governmental organizations (NGOs), international NGOs (INGOs), and advocates in the disability space, instruments and guidelines on disability data collection and analysis are available. Using common data collection tools, such as the Washington Group questions on disability, enables more collective analysis of data to inform response.

Where the humanitarian community needs a much greater understanding and set of principles and guidelines is in the collection, analysis, and use of data from diverse SOGIESC individuals. The latter is not as straightforward as sex, age, and disability and, depending on the context, has significant "do no harm" implications. However, it is critical that the humanitarian community, working with local and national actors, invests greater resources in addressing how to best understand the needs of and serve diverse SOGIESC populations in humanitarian emergencies.

An additional and critical gap relates to the adaptation of a more intersectional approach across individual, household, and community characteristics. For instance, being a woman, a child, and/or a person experiencing disability does not in itself make someone universally vulnerable. It is rather the interplay of identities and barriers in any given context that affects capacities, exacerbates vulnerability, or increases resilience. To illustrate, a young healthy girl may experience more vulnerability than a disabled older man of her same class and ethnic group. Across our review of the literature and through key informant interviews, we found scant evidence that organizations were looking at age, sex, disability, or diverse SOGIESC in consort. For example, disability should be both a variable to disaggregate data on and a variable that requires further disaggregation itself. We recognize that there are endless permutations across characteristics that could be considered in an intersectional approach. Nevertheless, we emphasize the need for disaggregation within and across sex, age, disability, and diverse SOGIESC when gathered. Guidelines on sex, age, disability, and other variables depending on the context and sector should be integrated to ensure more support for intersectional analysis.

It is worth noting that neither disability nor diverse SOGIESC, nor an emphasis on intersectionality, were highlighted in the 2011 *Sex and Age Matter* report, mirroring the state of the humanitarian communities' lack of emphasis on these identity factors at the time.

The humanitarian community needs greater investment in data management, analysis, use, and documentation. Most focus around sex-, age-, and disability-disaggregated data (SADD) is front loaded, with emphasis on data collection as opposed to analysis and using the data for program adaptation. However, there are opportunities to make better use of the data we already have. We can improve coordination across humanitarian actors working in the same context to reduce the burden on over-surveyed participants. We can make greater use of secondary data analysis. We need to invest in data dashboards so the already collected data can be made available to local and government actors, as well as external experts, for continued use and learning. Investment in this type of data management requires additional and continued funding and dedicated data management experts.

Turning the data collected into action to inform and shape humanitarian response is the biggest data-related gap identified throughout the research for this report. While some interviewees provided anecdotal evidence of program adaptation based on disaggregated data collection, the documentation of how programs were changed was rarely available. Agencies and funders need to prioritize setting aside time and resources to better document how the data are used so that the humanitarian sector can improve collective learning and accountability.

To achieve progress in the collection, analysis, and use of disaggregated data, a concerted and combined push across donors, governments, advocacy groups, and NGO headquarters is required. We found that the greatest progress since the 2011 *Sex and Age Matter* report, though with significant room for improvement, occurred in the collection and use of sex-disaggregated data and gender analysis, renewed focus on adolescents, and making disability visible. What all three of these stories of progress have in common is that mandates, guidelines, funding, and advocacy were not done in isolation but rather were undertaken by several organizations aligned on the topic over significant periods of time to change the conversation, not just the data. More specifically, the progress that was

made required that: first, donors mandated and funded the collection of and reporting on disaggregated data. Second, organizations and donors prioritized having a dedicated person (e.g., a disability lead or a gender lead) to provide necessary assistance and knowhow. Third, key international humanitarian standards and policies were created, such as the IASC 2017 Gender Equality and the Empowerment of Women and Girls in Humanitarian Action Policy to provide mandates and guidance to agencies. Fourth, clear and useable tools and guidelines like the Rapid Gender Analysis (RGA) or the Washington Group Questions were developed, piloted, and advocated for. Fifth, the inclusion of key vulnerable populations was clearly prioritized across program reviews and evaluation.

In 2011, CARE International, the UN Office for the Coordination of Humanitarian Affairs (OCHA), and Feinstein International Center, Friedman School of Nutrition Science and Policy at Tufts University published the international report *Sex and Age Matter: Improving Humanitarian Response in Emergencies*. The report made a strong case for collecting and analyzing SADD and using gender analysis to inform efficient, effective, and impartial humanitarian response during climate disasters and armed conflict. The authors found there was emerging data collection guidance for humanitarian settings that required the collection of SADD.<sup>9</sup> For example, the 2011 Sphere Handbook and Humanitarian Charter and Minimum Standards in Humanitarian Response called for SADD as a minimum standard.<sup>10</sup> Nevertheless, the *Sex and Age Matter* authors found almost no instances in which lead agencies collected SADD properly, analyzed the data in context, used those findings to influence programming, and then carried out proper monitoring and evaluation to determine the effect on programming. Unfortunately, 11 year later this still remains the case<sup>11</sup>

It has been a decade since the original publication of *Sex and Age Matter*. What progress has been made in the collection and use of SADD and gender analysis? How have current standards and guidelines been applied, and what affect has this application had on humanitarian response? What progress has been made in better recognizing, understanding, and responding to persons of diverse SOGIESC experiences and needs during a disaster? How can disaggregated data go beyond sex and age and begin to be more inclusive of disability and diverse SOGIESC? How are organizations considering the intersectionality of sex,



age, disability, and diverse SOGIESC in their data collection, analysis, and programming? And is sex, age, disability, diverse SOGIESC, and intersectional analysis leading to more effective programming?

In this updated report we seek to answer these questions. In this contemporary update, we go beyond the 2011 *Sex and Age Matter* report focus on sex and age. We document and analyze progress, barriers, and challenges to the collection, analysis, and use of disaggregated data and intersectional analysis to shape humanitarian response. We identify where progress has been made in terms of the availability of toolkits, guidelines, instruments, and donor policy to allow for the collection, analysis, and use of disaggregated data. And while the aim of this report is not to identify what group is most vulnerable, through case studies, we highlight how the use of disaggregated data and gender and intersectional analysis matters for policies, strategies, and programs to use an evidence-driven approach to respond to some of the most urgent and complex challenges humanitarians face now and will face in the future.

The progress that has been made around the inclusion of sex disaggregation and gender analysis can be specifically credited to decades of work by feminists and women's advocacy groups. Notably, the collection of SADD to inform humanitarian work with participants is now required by the leading donors of humanitarian assistance. The Sphere Standards and the SDGs further help enforce the collection and analysis of data by sex and age, while simple, clear, and usable guidelines such as the RGA allow for easy and quick application in the field.

As a result, many humanitarian organizations *claim to* use on sex and age as key factors in collecting data and determining need and vulnerability. However, in reality, this is often not the case. The use of sex-disaggregated data and gender analysis to inform programs, humanitarian needs overviews, and humanitarian response plans is rarely consistent or documented. In 2020, one half of the Peer-to-Peer humanitarian missions did not incorporate gender priorities and 45% of humanitarian needs overviews lacked any reference to sex-disaggregated data and gender analysis.<sup>12</sup> When it comes to age, guidelines around how age should be disaggregated are not always sufficiently granular, with the exception of a recent increased focus on adolescence, and the child nutrition and education sectors.

More recently, there has been an increase in the emphasis on disability-disaggregated data collection and use. Key factors include the launch of the “Charter on Inclusion of Persons with Disabilities in Humanitarian Action”<sup>13</sup> at the World Humanitarian Summit in May of 2016, the development of a standardized instrument—the Washington Group Questions—to collect disability data, and the SDGs’ requirement for some disability-disaggregated data. These have all helped to start putting disability on the radar. The importance of SADDD is further highlighted in the updated 2018 Sphere Handbook:

At a minimum, good practice encourages disaggregation by sex, age, and disability. Additional factors should be based on context. Analysis of disaggregated data is necessary to using standards in context and to monitoring. Good use of disaggregated data can show who has been most affected, who is able to access assistance and where.<sup>14</sup>

The rights of people with diverse SOGIESC are an extremely important but highly contested category that requires consideration as humanitarian policy and programming seek to be more inclusive and needs based. People with diverse SOGIESC can face specific vulnerabilities in humanitarian crises but are often made invisible due to lack of data collection. National policies that make homosexuality and any form of diverse SOGIESC illegal in some humanitarian contexts increase the risk to these people. However, some precedence and guidelines for safely working with diverse SOGIESC people in humanitarian contexts do exist, along with passionate local organizations working with those with diverse SOGIESC in many countries.

Moreover, only factoring in sex, age, disability, or diverse SOGIESC can have a flattening effect on the actual needs of individuals, households, and communities. The “single axis” approach is at odds with both the intersectional identities and social categories that individuals live within and must navigate when experiencing disaster and trying to access relief. A more intersectional approach<sup>15</sup> that is informed by how identities intersect to determine vulnerability and/or resilience is more reflective of actual humanitarian need. For instance, while older people can experience specific risks in complex crises beyond what healthy children and adults do, the intersection of disability and age can further

affect their ability to be informed about and access critical humanitarian services. A person experiencing disabilities faces specific risks in humanitarian emergencies that can be life-threatening, such as lack of communication, limited mobility, and transportation capacity, and mental or intellectual impairments that weaken decision making in stressful and difficult situations. However, when overlapping with sex, vulnerabilities as a result of disabilities are often heightened and exacerbated. For example, women and girls experiencing disability deal with multiple and intersecting forms of discrimination based on age, ethnicity, religion, nationality, socioeconomic status, and more. These intersecting forms of discrimination are exacerbated in conflict and displacement situations, where women and girls might face a variety of violations, including violence, abuse, and exploitation. Similarly, those with diverse SOGIESC also experience conflict and crises differently than do those who present as cisgendered or heteronormative, and these differences are not necessarily consistent across contexts and disasters, nor across wealth, race, or disability.

To further drive the point that considerations for sex, age, disability, gender, and intersectional analysis are critical for understanding and addressing vulnerability in humanitarian contexts, we present two case studies in the report (Chapter 3). The first case study looks at the 2013–2015 Ebola epidemic in West Africa. At the time of the crisis, programs and policies did not utilize age- and sex-disaggregated data, or gender and intersectional analysis. A review of the data shows extremely contrasting needs and vulnerabilities across sex and age groups when it came to infection, transmission, and impact on income and livelihoods, as well as a resulting increase in gender-based violence (GBV) and teen pregnancy. The second case study specifically focuses on the high level of disability and how it intersects with sex and age in populations that experienced the 20+ year civil war in northern Uganda. It shows that even 10 years after the war's cessation, women experiencing disability have increasingly worse outcomes that are not reflected in the response of government or NGO programming and targeting.

Most interviewees for this report stated that good, disaggregated data collection is important for humanitarian programming when properly analyzed and used. They also highlighted some significant gaps in relation to sex, age, disability, or diverse SOGIESC. Irrespective of the indicator—sex, age, disability, diverse SOGIESC—the biggest gap they

identified was in using the data to ensure that investment in funding and time of field staff and participants translated directly into program amendments. While there was some evidence of how disaggregated data impacted programs, it was not always consistent, and in only in a few cases was it documented. The gap in how disaggregated data translated into program change was referenced even in regard to sex-disaggregated data and gender analysis, where the humanitarian community has made the most relative progress. Closely linked was the question of data use more broadly. There was a general sense that after data are collected and reported, say to fulfill the Sustainable Development Goals (SDG), donor, or headquarter (HQ) requirements, they no longer had any perceived use and were shelved. There is a clear need for greater investment—including in terms of time, experts, and funding—in data management, data sharing, data dashboards, and documentation as one step towards better data use and accountability.

Another identified gap was the need for more expertise and funding to hire gender specialists to analyze and make sense of disaggregated data. Research finds that gender expertise is still often lacking. In 2019, only 33 percent of the Global Clusters had gender focal points. In 2020, only 19 percent of the Humanitarian Country Teams had appointed staff for Gender Capacity.<sup>16</sup>

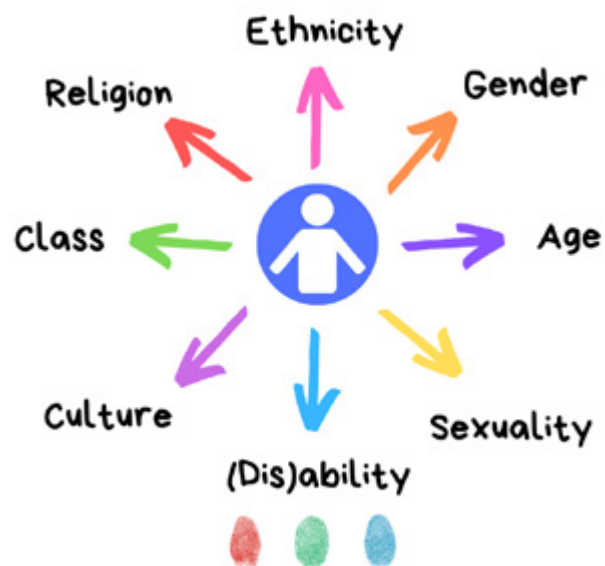
Research in 2020 on the five IASC associated entities - the Global Cluster Coordination Group, the Gender Reference Group, the Mental Health and Psychosocial Support Group, the Inter-Agency Humanitarian Evaluations Steering Group and the Humanitarian Program Cycle Steering Group - found three of the five groups failed to produce any specific integration of gender in their key deliverables. Only the Gender Reference Group and the Inter-Agency Humanitarian Evaluations Steering Group presented gender integration into their deliverables.<sup>17</sup>

Expertise specific to disability, diverse SOGIESC, data management and data inclusivity, and older persons even less common. Without the relevant knowhow coming from an expert or dedicated lead, it is difficult to know what to analyze and how to translate it into programming. In addition, if further data collection requests are made, such as around people experiencing disabilities or those with diverse SOGIESC, funding and resources for training would need to complement additional data collection and analysis needs.

There was also a clear hierarchy in gaps depending on the intersecting identity, with the least amount of knowledge and work done around diverse SOGIESC people. Greater understanding around the needs of diverse SOGIESC individuals in humanitarian crisis needs to be prioritized.<sup>18</sup> The legal precarity of diverse SOGIESC people in some humanitarian contexts alongside the limited—but existing—guidelines<sup>19</sup> on how to collect data safely and ethically on and program for diverse SOGIESC identities were cited as some of the main reasons why diverse SOGIESC individuals are so rarely considered in humanitarian data collection, targeting, and programming. However, neither reason is sufficient for determining that humanitarian agencies cannot work with diverse SOGIESC people in a meaningful and effective way. The starting point is to work with SOGIESC organizations already working at the national or local level to understand the context and group priorities before any individual-based research is conducted. Efforts are underway for a more concerted effort across the humanitarian community to think about how to “do no harm” and better understand and address the needs of diverse SOGIESC people, as we detail later in the report.

Applying an intersectional lens to data analysis was the next key gap that was apparent, with few organizations reporting the use of intersectional analysis. The possibly endless permutations of variables to consider for intersectional analysis can make it appear a daunting task. However, the reality is that intersecting identities, as opposed to a “single axis” approach, are far more relevant in understanding vulnerability, resilience, and capacity (Image 1). When it comes to sex, age, and disability variables, data should be analyzed across and within these categories: what are the specific needs of girls and boys experiencing disability, or of older women and men, etc.? Additional considerations depending on the context, such as wealth, race, ethnicity, urban/rural, and livelihood might need to be considered. The more in-depth intersectional analysis beyond sex, age, and disability requires additional local and cultural expertise and is dependent on the context and crisis. Where possible, an investment in understanding the role of intersectional identities that can inform data analysis should be made, but only with complementary expertise and funding.

**Image 1: Intersectionality** (\*Reproduced from <https://medium.com/dna-s-blog/identity-beyond-disability-3d59d19b1dad>)



Compared to age and sex, a focus on people experiencing disability is at its infancy. However, almost every organization or funder interviewed for this report said they are either already working on disability or in the process of putting in place guidelines, mandates, and recommendations around disability. There is a growing discussion with disability experts about how to prioritize disability in humanitarian response. There is also the exemplary case of Australia’s funding body—Department of Foreign Affairs and Trade (DFAT)—which has mainstreamed disability across all projects and programs. The availability and use of disability-disaggregated data are still limited as are programs addressing disability, but there are guidelines, standardized instruments, and organizations that are available to appropriately center disability alongside sex and age. As with the progress on sex and gender analysis, and the focus on adolescence, the growing focus on disability comes from work done by disability advocates and groups that have produced a variety of international documents highlighting disability as a human rights issue.



A final critical gap relates to the disaggregation of age data. While age is at times collected and somewhat frequently analyzed, how age data are disaggregated remains insufficient. Simple and wide age brackets can obscure the specific needs of certain age groups. And while there has been a growing emphasis on adolescence and youth, older persons are often lost in aggregation and therefore made invisible. However, in the few examples where data on older persons were collected, particularly the intersection of older persons and persons with disabilities, it is clear that they have immense, growing, and specific needs in humanitarian crisis. Now is the time for a more focused prioritization of analyzing granular age data to better capture and program for the needs of older persons.

### Study Methods

This report uses three key sources for data collection: focus group interviews with a Delphi panel, key informant interviews, and a thorough literature review. The Delphi panel was comprised of 26 humanitarian experts who have been part of collection or policy teams that have used sex, age, disability, diverse SOGIESC, and gender and intersectional analysis in their work. Additionally, the researchers carried

out 23 in-depth interviews with key informants regarding their humanitarian work and the use of sex, age, disability, diverse SOGIESC, and intersectional analysis. In total we interviewed 49 subject experts. We also conducted an extensive literature review to build on the knowledge regarding sex, age, disability, diverse SOGIESC, and gender and intersectional analysis that has been published since the 2011 *Sex and Age Matter* report.

### Report Overview

Chapter Two presents the current state of analyzing, collecting, and using sex-, age-, disability-, and diverse SOGIESC-disaggregated data, and gender and intersectional analyses to inform humanitarian policy and practice. We chart where progress has been made and how, as well as where the humanitarian industry is developing and where many want to see it go. Chapter Three offers two in-depth case studies that show the value added of using disaggregated data and intersectional analyses to better understand and hence respond to some of the most pressing matters facing humanity and humanitarians: epidemics and disability in war and disaster. Chapter Four offers conclusions and a series of actionable recommendations.







## CHAPTER 2 Sex and Gender Analysis, Diverse SOGIESC, Age, Disability, and Intersectional Analysis and Use in Humanitarian Practice

What is the current state of collecting, analyzing, and using sex-, age-, disability-, diverse SOGIESC-disaggregated data, and gender and intersectional analysis to inform and shape humanitarian practice? The quick answer is that we have made some progress, learned key lessons, developed important standards, frameworks and tools, and seen some changes and gains in how humanitarian assistance is conducted. We have made some progress regarding sex-disaggregated data and gender analysis. We are getting better with age and are starting to consider and incorporate disability data collection and analysis. We remain hesitant around how to consider diverse SOGIESC in data collection. Overall, we rarely incorporate intersectional analysis of disaggregated data.

In this section, we draw upon our interviews and the literature to review the progress that has been made, to outline existing barriers to further progress, and to highlight where the humanitarian community wants to go when it comes to sex and gender analysis, diverse SOGIESC, age, and disability data collection, analysis, and use, as well as more intersectional approaches. We include a section specifically on data management, analysis, and use, as these topics were raised across the interviews irrespective of whether we were

discussing sex, diverse SOGIESC populations, age, disability, or intersectionality. We end with a concise conclusion and actionable recommendations.

### Sex Specific Data and Gender Analysis

Sex specifically refers to the label of male or female based on different biological and physiological characteristics at birth, while gender refers to the socially constructed characteristics of women and men, girls, boys, and those with diverse SOGIESC, including norms, roles, and relationships. Thus, gender analysis is a complex analytical tool. Gender analysis factors in the relevance of gender norms and power regarding roles, rights, and relations among different genders. It considers gender inequities and their structural causes, and examines the needs, constraints, and opportunities available to different genders within the broader context. Finally, gender analysis identifies gaps, discriminations, and inequalities among the genders and comes up with ways to address harms, address rights violations, do no harm, and promote equity, inclusion, and empowerment. In this section we look at the state of humanitarian collection and use of to sex-disaggregated data and gender analysis to inform humanitarian response.

The push for collecting sex-disaggregated data and using gender analysis to make a difference in humanitarian crises is the result of twenty-plus years of work by feminist and women’s rights advocates inside and outside of the humanitarian industry:

The humanitarian community was only focused on water, shelter, health from its inception. So, the conversation we see now around gender and how that intersects with water and shelter and so on did not happen naturally. Feminists pushed the humanitarian and development communities to take gender and sex seriously, and they faced a lot of pushback. They kept insisting, “We need to have this conversation, it’s intersecting everything we are doing”...It wasn’t just evidence that caused the shift to pay attention to gender and sex—it was evidence paired with advocacy, paired with lots of expertise, paired with some really solid programming, paired with getting specific donors to invest in and be on board with the conversation.<sup>20</sup>

Today, most of the leading national, international, and intergovernmental donors to major humanitarian agencies have standards that direct humanitarian agencies to collect and use sex-disaggregated data and carry out gender analysis in their work with participants. To illustrate, the collection and use of sex-disaggregated data and gender analysis is a component of USAID guidelines and requirements.<sup>21</sup> The Directorate-General for European Civil Protection and Humanitarian Aid Operations (DG ECHO) adopted a Gender and Age Marker that has four criteria that all partners working with participants must apply. The criteria include the collection and use of SADD and gender analysis.<sup>22</sup> Other principal donors similarly highlight and require the need for SADD.<sup>23</sup> Of note, in 2015, the SDGs were launched and required sex and age disaggregation on most all indicators using individuals and households. “Now everyone wants SADD because the SDGs require that [most] all data should be disaggregated” to track progress to achieve the SDG goals.<sup>24</sup>

As stated by UN OCHA, five elements comprise the humanitarian programming cycle: 1) needs assessment and analysis, which specifically highlights the need for collection of SADD and gender analysis, 2) strategic response

planning, 3) resource mobilization, 4) implementation and monitoring, and 5) operational review and evaluation<sup>25</sup>. We’ll refer to these five elements in our review below.

According to an interviewee from UN OCHA:

Gender analysis is one of the key areas we are trying to strengthen and support our offices on because we do see that as the baseline. If you have good gender analysis you can do better humanitarian programming. And, in order to do that, you have to have disaggregated data, not just collecting it, but to analyze it and use it in a meaningful way. In the humanitarian program cycle, there are templates and guidance that reference a strong need for SADD.<sup>26</sup>

There are a number of SADD and gender analysis guides in humanitarian programming standards, policies, guidelines, tools, and gender and age markers. They cover the range of humanitarian programming across the program cycle. For example, according to a humanitarian official we interviewed:

The Inter Agency Standing Committee Gender with Age Marker tool that we promote to humanitarian actors is a great tool to help prompt them to consider gender in their work, from design through to monitoring, evaluation, and learning. With the use of that tool, we see more gender, age, and other factors informing humanitarian action.<sup>27</sup>

A DG ECHO official relayed the improvements seen since their Gender Age Marker came into force:

We found that 89% of EU [European Union]-funded humanitarian aid took gender and age consideration into account—this has risen from the first assessment. We are always looking to beef that number up, but we also need to keep in mind that it will never be 100% because we don’t require partners to use the Gender and Age Marker if the aid does not include any beneficiaries.<sup>28</sup>

According to a respondent from a humanitarian INGO:

For impact measurement we have a standard that we need sex disaggregation. Then depending on the thematic area and what you're measuring we have 30 suggested metrics for different topics, and each of them has specific recommended disaggregation...Over time, mostly on the humanitarian work with the Rapid Gender Assessment that has become more present, we have started to put more attention to collecting and discussing sex-disaggregated data to inform our response.<sup>29</sup>

Most of the experts and practitioners we interviewed stated that over the last ten years, humanitarian donors and organizations are more inclined to recognize and act on (some faster than others) the importance of using sex-disaggregated data and gender analysis to inform humanitarian programming. According to an official from one of the largest humanitarian INGOs:

There has been a shift over time. Having the gender marker as a tool that's used constantly over time and is given importance by the organization's leadership does mean that people are thinking much more about gender integration in programs. Gender has moved from being something that was talked about a little bit ten years ago, to being one of our three core approaches five years ago. Now it's the heart of our whole strategy for the next ten years.<sup>30</sup>

The above developments and statements sound very promising. But how do such purported advancements and proclamations measure up to the actual data humanitarian agencies produce regarding sex-disaggregated data and gender analysis in their humanitarian programming cycle?

One of the most important findings of our research is that nearly everyone in the humanitarian industry we interviewed has the strong perception that their agencies are regularly and systematically collecting and using sex-disaggregated data and gender analysis to inform their humanitarian programming cycle. Yet the data and evidence to support these claims is rarely present and, in a number of cases, non-existent. In fact, almost no agency personnel we interviewed

could produce actual documentation on their organizations use of sex-disaggregated data and gender analysis throughout the programming cycle and the difference, if any, it made to crises affected populations (a finding also flagged in the original *Sex and Age Matter* report).

Lack of documentation is a pervasive problem in the humanitarian sector and is not limited to sex and gender analysis. Clearly, there is an urgent need for donors to incentivize and provide funding for the time and resources needed and for agencies to prioritize time and resources to document how the use of sex-disaggregated data and gender analysis is being used and with what results.

One of the most rigorous gender analyses of data from current humanitarian programming comes from UN Women's *2020 Gender Accountability Framework Report*, the third such report to monitor the implementation of the IASC's 2017 Gender Equality and the Empowerment of Women and Girls in Humanitarian Action Policy. The latest report provides data on the IASC's output for calendar year 2020 and enables comparison to the previous two years reports

Briefly, the IASC's 2017 Gender Equality and the Empowerment of Women and Girls in Humanitarian Action Policy "is a framework that specifies principles, standards, and actions that IASC Bodies, Members and Standing Invitees should abide by at global and field level to integrate gender equality and the empowerment of women and girls into all preparedness, response and recovery efforts."<sup>31</sup> The policy is clear and unequivocal:

The IASC commits to the goals of gender equality and the empowerment of women and girls in humanitarian action. This entails making provision to meet the specific needs of women, girls, men, and boys in all their diversity, promote and protect their human rights, and redress gender inequalities.<sup>32</sup>

Laying out standards, the policy requires, in part, that "all IASC Bodies, Members and Standing Invitees":

Carry out joint context-specific gender analyses, with the collection of sex and age disaggregated data (SADD), to identify the gender inequalities that lead to different power, vulnerabilities,

capacities, voice and participation of diverse women, girls, men, and boys, and how these intersect with other inequalities. Use the results of gender analyses to inform humanitarian action at each stage of the HPC [humanitarian program cycle].<sup>33</sup>

The policy and actions are very clear. However, UN Women found that in 2020, the collective actions of the IASC at the global level fell short on nearly every standard set out by the 2017 Gender Equality Policy.

Both UN OCHA's guidelines on Humanitarian Needs Overview (HNO) and the IASC's 2017 Gender Equality and the Empowerment of Women and Girls in Humanitarian Action Policy state that SADD and gender analysis are required to inform the first stage of the humanitarian programming cycle – the HNO. The HNO then informs the Humanitarian Response Plan.

In reviewing IASC HNOs in 22 emergencies, UN Women found considerable unevenness in the use of SADD and gender analysis. In 2020, only 55% of the HNOs met the *minimum* criteria – demonstrating some use of SADD in at least half of the included clusters/sectors - for the use of SADD and gender analysis. Notably, this number rose to 70% when Gender Working Groups were active. In 2018, the presence of SADD and gender analysis was 45% and in 2019 47%, so there has been incremental improvement, and there is still a long way to go.<sup>34</sup>

Importantly, there was enormous variability in the depth, rigor, and usefulness of those 55% of Needs Overviews that even met the minimum gender criteria. In a case that illustrates what a sound and robust SADD and gender analysis looks like,

The HNO for Afghanistan clearly articulated the specific needs of diverse women and girls, including those of women-headed households, women and girls with disabilities, pregnant and lactating women, and the specific challenges and risks faced by girls. Covering a wide array of needs, the HNO drew attention to women's and girls' increased care burden, heightened risk of GBV, nutritional needs, further reduction

in access to and control over already limited resources, and health needs spanning from psychosocial care to sexual and reproductive concerns.<sup>35</sup>

Other cases met only the bare minimum criteria for inclusion, and in doing so they fail to meet the intent of IASC Gender Equity policy standards. For example, the Humanitarian Needs Overview for Somalia made vague and passing references to GBV and reproductive health and offered no context specific information on women and girls in the country or crises. How can such a needs overview adequately inform a response plan to address the needs and rights of Somali women and girls? Equally concerning, in the humanitarian needs overview of Mali and Iraq, there was no use of SADD or any kind of gender analysis.

We conclude that the use of sex-disaggregated data and gender analysis is too often still not occurring at the levels and with the rigor that is necessary to meet the commitments made to women and girls in IASC's 2017 Gender Equality and the Empowerment of Women and Girls in Humanitarian Action Policy. Instead, too often, we find poorly informed Needs Overviews failing to fully inform Humanitarian Response Plans, which in turn leads to weak to non-existent planning and programs that fail to take women's and girls' particular needs into account (see below).

Notably, according to the authors of UN Women's *2020 Gender Accountability Framework Report*, having strong SADD and gender analysis in the HNO is no guarantee that it will be translated into what is prioritized in the final Humanitarian Response Plan. The researchers documented Humanitarian Response Plans that did not reflect the findings from their SADD and gender analysis that the teams presented in the Humanitarian Needs Overview. And in nearly half of the plans (42%) the Humanitarian Country Teams did not include any women's organizations in developing the humanitarian needs overview or the response plans.

Table 1 illustrates this disconnect at the level of the Clusters and reveals how in too many cases, a poorly informed system that fails to use SADD and gender analysis in the Needs Overviews, results in incomplete and biased Response Plans and the resulting lack of smart and gender-informed programming for women, girls, men, boys, and those with diverse SOGIESC.



**TABLE 1****Breakdown of the use of SADD in clusters across 22 country Humanitarian Needs Overviews**

HNO	Cluster										
	% of clusters using SADD	CCCM	Education	Early Recovery + Livelihoods	Food Security	Health	Nutrition	Protection	Shelter + NFI	WASH	Refugees & Migration
Afghanistan	100%		y		y	Y	y	y	y	y	
Burkina Faso	57%		n		y	Y	y	y	n	n	
Burundi	43%		y		n	N	y	y	n	n	
Cameroon	56%		y	n	y	Y	y	y	n	n	
CAR	100%		y		y	Y	y	y	y	y	
Chad	38%	n	n		n	Y	y	y	n	n	
DRC	75%		y		n	N	y	y	y	y	n
Ethiopia	38%		y	n	y	N	y	n	n	n	
Haiti	100%		y		y	Y	y	y	y	y	
Iraq	0%	n	n	n	n	N		n	n	n	
Libya	33%		y		n	N		y	n	n	
Mali	43%		y		n	N	y	y	n	n	
Myanmar	14%		n		n	N	y	n	n	n	
Niger	71%		y		n	Y	y	y	y	n	
Nigeria	67%	n	n	y	y	Y	y	y	n	y	
oPT	83%		y		y	Y		y	n	y	
Somalia	88%	y	y		n	Y	y	y	y	y	
South Sudan	100%	y	y		y	Y	y	y	y	y	
Sudan	100%	y			y	Y	y	y	y	y	
Syria	33%	n	n	n	y	Y	y	n	n	n	
Ukraine	100%		y		y	Y		y	y	y	
Yemen	67%	n	y		n	Y	y	y	n	y	y
<b>Total</b>		<b>38%</b>	<b>71%</b>	<b>20%</b>	<b>55%</b>	<b>68%</b>	<b>100%</b>	<b>82%</b>	<b>41%</b>	<b>50%</b>	<b>50%</b>

Note: Empty entries indicate that this cluster was not included in the corresponding HNO

Table reproduced directly from The Gender Accountability Framework Report - 2020, pg 25 and 26

Nearly everyone in the humanitarian industry that we interviewed for this study had the strong perception that their agencies are regularly and systematically collecting and using sex-disaggregated data and gender analysis to inform their humanitarian planning and programming. Yet the data and evidence to support these claims is largely not available. What is going on?

Several intersecting factors explain what is happening and why. First, the standards, mandates, policies, requirements frameworks, guidelines, and templates to collect and use sex-disaggregated data and gender analysis are in large part available to those within the humanitarian industry at all five levels of the humanitarian programming cycle. What is too often lacking are the will and means to hold humanitarian actors and agencies accountable to their gender equity commitments.

The bottom line is accountability. It's written into guidelines in black and white in the IASC gender policy and roles and responsibilities. OCHA and others have guidelines on how to develop an HNO and an HRP that include SADD and gender analysis, etcetera etcetera. It's all in there in black and white. But it isn't being done consistently and nobody is being held to account for it. UN Women does the Gender Accountability Framework report year in and year out and provides a set of recommendations at the end, of which it always includes SADD and gender analysis in the planning phases and response plans. But it's very difficult to see that those recommendations are being picked up. Different evaluations on gender marks the lack of use of sex disaggregated data and gender analysis, true, but they also must focus on the lack of accountability for not doing so.<sup>36</sup>

For international humanitarian agencies and organizations, it is imperative that they have senior people with gender expertise properly positioned to ensure accountability for gender standards. According to a researcher looking into the disconnect between the IASC 2017 Gender Equality and the Empowerment of Women and Girls in Humanitarian Action Policy and the actual results of humanitarian programming cycles within the IASC,

At the global level, the lack of accountability in large part is because the IASC Principles do not have gender expertise capacity in place. They don't have someone at the table to bring up and ensure gender is taken into account in the

humanitarian programming cycle. UNFPA is an IASC Principle, but they focus on GBV and sexual and reproductive health, which are hugely important, but they do not encompass all that gender expertise can bring. The lack of accountability for gender at the top, whether IASC or international NGOs, that is a huge contributor to why that isn't trickling down. And when gender is not championed and enforced from the top, it's always advocates scrambling around after the fact or gender being ignored.<sup>37</sup>

Second, there is still a lack of specific gender expertise and capacity in each crisis context. This gap means that too often there is no one dedicated to advise the country teams and clusters and to ensure the specific sex and gender standards are adhered to. In fact, in 2020, only 18-20% of crises had sustained gender capacity in place.<sup>38</sup>

There are crises that have Gender Standby Capacity Projects (GENCAPs), but they are temporary positions. The crises we are looking at are years long. The GENCAP often comes at the beginning and has shown to be highly effective. Yet several months later when they are gone, gender starts to fall off the radar. Unfortunately, nobody wants to fund gender coordination. There is a gender funding myth – everyone agrees that gender coordination is really important, but nobody wants to fund it.<sup>39</sup>

Gender expertise and accountability is needed at the top, *and* gender expertise is needed at the Humanitarian Country Team, the Cluster Level, and at the technical working level. To illustrate,

In [name withheld country], there was someone working in the OCHA office to integrate gender and there were about 20 out of 26 indicators that were relevant to SADD and gender, and this person had the ability to ensure the collection of SADD. The gender informed data we were getting in from the clusters in that crisis was excellent. Then three months later, the gender expert was gone, and we looked again at the data coming in from the same clusters and we are seeing no SADD or gender specific data so those columns. They were empty or they would say 2000 men 2000 women, which really raises the question

of how accurate that kind of data is. When you insist on SADD without capacity or support on the ground at the Cluster level, what you are going to get is data you cannot rely on. Without expertise they will leave it blank, or they are just going to do 50/50. So, you have questions about maturity of the humanitarian system to meet their own mandates and to bring on and sustain gender expertise where we need it.<sup>40</sup>

As one interviewee succinctly stated, “We can’t have a gender-equal world without putting resources to it—which includes the people who collect and analyze data, design, and implement programs, and continue the advocacy.”<sup>41</sup>

Third, project level gender expertise and adherence to SADD and gender analysis is essential, but on its own it is not enough to influence the humanitarian system. Many of the people we interviewed spoke of the use of SADD and gender analysis at the program level, where they stated such work was being undertaken. Again, almost no documentation of these efforts was available. According to a humanitarian official, regarding the undocumented gender efforts at the program level,

They may be doing extremely elaborate SADD but there is no evidence they are using it. So, if they are doing it, they are wasting their time [by not using it] or they have a rich resource they aren’t utilizing properly.<sup>42</sup>

Commenting on the lack of sex and gender informed documentation by organizations, another senior humanitarian official at the global level said,

People do say it’s being collected more and more, but it’s at the project level. And it’s not elevated to the cluster level or the humanitarian level. There is little evidence that the data is used by the individual agencies or organizations, so maybe it is or maybe it isn’t. We cannot tell. But there is clear evidence it doesn’t feed into the overall humanitarian response. We can still acknowledge that people are collecting this data, but we must call for this data to be collected more systematically and moved into the organizations decision making and the overall humanitarian response. In preparing humanitarian response, we don’t have all the answers. If you can provide that gender analysis it can balance out what is needed, and then we can more systematically use the

data and ensure it feeds into the Needs Overview and the Response Plan.<sup>43</sup>

Fourth, the same excuses about insufficient time to collect the appropriate data keep being used to place SADD and gender on the back burner.

I was just in Ukraine and there was a real dearth of SADD being utilized and I questioned this. We get this narrative, “We don’t have time to do that, we are in a full-on crisis mode here, we will get to that to a later stage!” We hear, “This is a full-on crisis we don’t have time to stop for these considerations, we have to just focus on life saving activities!” But then UN Women and CARE’s rapid gender assessment of the war in Ukraine comes out and shows in technicolor detail that the Ukraine crisis is very gendered and if you aren’t looking at gender you aren’t getting it right – you are missing so many gaps and steps along the way in every direction of response.<sup>44</sup>

With clear standards and proven tools, like the RGA (Box 1), among others, such excuses are no longer valid, if they ever were. A UN official noted the importance of tools now available, particularly the RGA toolkit:

In this regard, the most efficient and recognized guidance on how to do this is the RGA Toolkit that CARE developed. That Toolkit allows for collection of gender qualitative and quantitative data, and that I believe has made it possible to make a lot of headway in making data collection accessible.<sup>45</sup>



## BOX 1

### Rapid Gender Analysis Guidelines and Training

CARE first developed the RGA approach and tool<sup>46</sup> in 2013 as part of their humanitarian response in Syria. The goal of the toolkit is to provide essential information on gender roles and responsibilities, capacities, and vulnerabilities together with programming recommendations given limited time and resources. The RGA toolkit provides a clear and simple step-by-step guide that is easily adapted to different geographic and cultural contexts. Most recently, it was adapted for humanitarian assistance during COVID-19. The tool is publicly available online in multiple languages with annual trainings on how to use it to integrate intersectional gender analysis and apply it to daily work, projects, programs, and governance.

A recent evaluation of the effectiveness of the RGA found strong evidence that it has led to an increase in the availability of robust gender analysis and data. More so, the evaluation found that where RGA have been undertaken, new and existing program and project activities and strategies have been adapted to better recognize the different needs, roles, vulnerabilities, and capacities of men, women, boys, and girls.<sup>47</sup> However, gaps remain, with limited capacity for data analysis as a constraint for both the RGA process and quality, frequently requiring external assistance. In addition, serious obstacles remain in the consistent translation of findings from the RGA into direct implementation.

Despite not being mandated, the RGA tools have become institutionalized and widely recognized as integral to humanitarian response due to a combination of demand-driven “pull” factors and institutional “push” factors, resulting in increased adaptation and implementation. The development of the tool and its refinement was a decade-long process and can serve as a model for how the availability of clear and concise tools and respective capacity training can increase the use, understanding, and adaptation of SADD.<sup>48</sup>





Throughout our research, and across continents, interviewees noted the effectiveness of using the RGA (Box 2).

## BOX 2

### Rapid Gender Analysis Impact on Programming in Bangladesh

In Bangladesh, CARE and UN Women made several programming changes based directly on the findings from an RGA. In 2020, The Gender in Humanitarian Action Working Group comprising of UN Women, UNFPA, UNICEF, CARE, World Vision, Plan International, and the Resident Representative's Office, undertook the COVID-19-adapted RGA.<sup>49</sup> The RGA highlighted that COVID-19 was seen as a punishment from God for “dishonorable” actions carried out by women, such as failing to observe purdah, which is the practice of women living in a separate room, or behind a curtain, or dressing in specific clothing in order to stay out of sight of males and strangers. The result of this belief led to even greater policing of women and girls, limiting their access to services, and contributing to GBV.

In direct response to these findings from the RGA, CARE Bangladesh started an information tracking system and implemented activities with religious leaders to reduce social stigma for women who might violate purdah.

The RGA also revealed that women have less access to lifesaving information compared to men. Many sources of information are accessible only to men through mobile networks, tea stalls, and mosques.

In response, CARE Bangladesh strengthened their “communication with communities” approach to make sure that up-to-date health information was equally available to women through door-to-door messaging on disease as well as training female volunteer health workers to specifically target women, older persons, and people with disability.<sup>50</sup>

Fifth, throughout our interviews we found that advocates in government and intergovernmental organizations and humanitarian organizations too often still had to fight to get sex and gender analysis appropriately prioritized and resourced within their organizations and the humanitarian industry as a whole.

I don't think evidence by any means is something that the humanitarian community solely acts on. We need the advocacy and evidence and everything else to move the sex data conversation forward. It's going to take way more than evidence. It really requires experts to be deploying and showing and proving that not only can it be done, but that it's useful and that it can be done in a way that is relevant to the people and the organization involved.<sup>51</sup>

You will see that in most of the humanitarian response plans and strategic documents SADD is being collected. Exactly how much that informs individual agencies' programming is the part that we are not so clear on.<sup>52</sup>

Thus, while advocacy continues to be integral for making sure sex-disaggregated data and gender analysis is part of every humanitarian program, we can help underpin it by documenting and evaluating how applying these tools and conceptual analysis directly improves programming and leads to more efficient use of dwindling humanitarian resources in the face of growing need.

Sixth, several interviewees highlighted that in some cases, even with the presence of data, assumptions around vulnerability – who is most vulnerable and who is less vulnerable - prevail and guide humanitarian response. To illustrate, we present a case on the different effects of violence on women, men, and boys from Cameroon (Box 3).<sup>53</sup>

### BOX 3

## Different Risks for Men, Boys, Women and Girls in Cameroon

The Norwegian Refugee Council's publication entitled *A Failure to Address the Vulnerability of Men and Boys* discusses the urgent need to pay attention to the unaddressed specific needs of men and boys in Cameroon. In a region where many lack official documentation, women are more often able to move freely through checkpoints, whereas men face much greater risks of being arrested for lack of identification by security forces in the country.

In the southwest region of Cameroon, males comprise 8 out of every 10 victims of “arbitrary arrests, beating, illegal detention, torture, kidnapping, extra-judicial executions and disappearance.”<sup>54</sup> The risks of men being disappeared, detained, arrested, or killed has led to a shift in gender roles: now women are increasingly more likely to be the primary breadwinner and participate in economic and social activities that were once relegated to men in the community.

Thus, the data point to the different priority needs of women—economic and livelihood support—and men—legal support and protection.

Humanitarian organizations and donors can use SADD and gender analysis in order to best determine how to shape support.<sup>55</sup>

Significant gaps and opportunities remain for improvement in terms of sex-disaggregated data collection and gender analysis. The humanitarian community, including donors, needs to create clear mechanisms to hold actors accountable in the documentation of processes and the impact of the use of sex-disaggregated data and gender analysis to continuously learn and evolve our learning, approaches, and programs.

### Diverse Sexual Orientation, Gender Identity and Expression, and Sex Characteristics

As the humanitarian community moves forward to continue to work and improve the collection of sex disaggregated data and gender analysis, greater consideration needs to be put on the expansion of our understanding of gender to include people with diverse SOGIESC.

The Humanitarian Advisory Group's “Taking Sexual and Gender Minorities Out of the Too-Hard Basket”<sup>56</sup> challenges the current belief that inclusion of individuals with diverse SOGIESC is too complicated for humanitarian actors. The Humanitarian Group toolkit recommends, as a starting point, making sure the organization's policies and practices are inclusive of sexual and gender minorities. The next step

is training or talking to staff about the importance of inclusion of people with diverse SOGIESC. Finally, the toolkit recommends building relationships and trust with local organizations representing sexual and gender minorities before a crisis whenever possible. In addition, the toolkit urges humanitarian actors to tweak standard categories around sex to include “other” as a bare minimum.<sup>57</sup> Talking to individuals who publicly identify as having diverse SOGIESC and including them in the humanitarian organization's needs assessment are also important. The toolkit cautions actors not to collect data on those with diverse SOGIESC if the actors know that these individuals are likely to experience discrimination, harassment, exclusion, and violence based on their response. The toolkit highlights that it is important to always work with and rely on local partners who have experience with and the trust of local diverse SOGIESC communities.

However, a focus on diverse SOGIESC is an area in which the humanitarian industry has shown the least capacity, interest, and willpower to assist this group of people who are in need during disaster. To illustrate, according to the Humanitarian Advisory Council, in 2018, there was 0% inclusion of diverse

SOGIESC in the 10 largest humanitarian response plans.<sup>58</sup>

What we learned from an official from one of the largest humanitarian INGOs in the world we found is reflective of much of the larger humanitarian industry as a whole:

Despite the fact that we serve hundreds of different ethnicities and language speakers, and a wide range of ages and different genders, lesbian, gay, bisexual and trans people are never accounted for in our data. That is just wrong, because we are not actually fitting the real needs, we are just regressing to the most powerful mean.<sup>59</sup>

When we asked another official from another leading humanitarian organization how they collected information about diverse SOGIESC populations, they replied, “We don’t. Look, it’s a little too ambiguous.”<sup>60</sup>

In preparation to speak with the authors of this report, an official at an international organization focused on international humanitarian coordination relayed:

I checked sector response plans to see if they included [anything on LGBT] and zero percent of the sector plans included these folks. The sector response plans included sex, age, and disability more often but for LGBT it was zero. There is a debate if this group of people should even be part of the humanitarian mandate.<sup>61</sup>

The European Union (EU) currently comprises 27 countries and member states, each with their own political perspectives. As such, the EU tries not to go against national administrations. As one of our EU interviewees explained:

You are probably very aware that there are a few member states that take a different approach from the majority on issues of gender, age, and LGBT—not so much on disability actually—but certainly on gender and LGBT.<sup>62</sup>

However, the issue of diverse SOGIESC populations in humanitarian emergencies is not completely ignored.

There is a group of humanitarian agencies and scholars that are directly engaging in developing standards, guidance, tools, and programs that will support the rights of those with diverse SOGIESC affected by disaster to humanitarian assistance. For example, the EU Commission has taken an independent stance on the importance of gender and the rights of individuals with diverse SOGIESC in emergencies.<sup>63</sup> In other cases, leading humanitarian INGOs are including individuals with diverse SOGIESC in data collection, program design, and response. As one humanitarian official explained:

Yes, we work closely with LGBT in Equator, Guatemala, and Honduras, particularly in the context of migration. There is so much migration happening in the region, and these communities are at a very high risk, particularly during COVID-19. So, our programs in those countries are doing more work with the trans and other parts of the LGBTQ community. Part of the reason we can and are doing this is that the pressure to address their needs is locally driven, there are local civil society partners we can learn from and work with, and there is a legal environment that can be used.<sup>64</sup>

Through the advocacy of committed organizations and individuals, there are now dedicated toolkits that highlight ethical and safe ways to incorporate those with diverse SOGIESC into humanitarian programming from the outset. These tools can help agencies with how to effectively consider ways to ensure that some of the most vulnerable among those experiencing disaster are not left behind.

Two important tools are Edge Effect’s “Diverse SOGIESC Rapid Assessment Tool to Assess Diverse SOGIESC Inclusion Results in Humanitarian Contexts,” which outlines how to include those with diverse SOGIESC into humanitarian programming, including survey instruments, qualitative questionnaires, and a rapid self-assessment tool humanitarians can use to evaluate their programs.<sup>65</sup> For example, a mixed methods study<sup>66</sup> reviewing existing survey tools for better identifying diverse SOGIESC found that by simply expanding the traditional male/female survey question to three questions, the survey tool can respectfully capture gender identify as well as lived gender (Box 5).



## BOX 5

### Multidimensional Sex/Gender Measure

1. What sex were you assigned at birth, meaning on your original birth certificate?<sup>67</sup>
  - a. Male
  - b. Female
2. Which best describes your current gender identity?
  - a. Male
  - b. Female
  - c. Indigenous or other cultural gender minority identify (e.g. two-spirit)
  - d. Something else (e.g. gender fluid, non-binary)

The third question may be asked only of those who indicated a current gender identity different than their birth-assigned sex. If so, it can be forward-filled to code cisgender participants as living in their identified (and birth-assigned) sex/gender.

3. What gender do you currently live as in your day-to-day life?
  - a. Male
  - b. Female
  - c. Sometimes male, sometimes female
  - d. Something other than male or female

Source: Bauer GR, Braimoh J, Scheim AI, Dharma C (2017) Transgender-inclusive measures of sex/gender for population surveys: Mixed-methods evaluation and recommendations. PLOS ONE 12(5): e0178043. <https://doi.org/10.1371/journal.pone.0178043>

In addition, the Humanitarian Advisory Group's "Taking Sexual and Gender Minorities Out of the Too-Hard Basket"<sup>68</sup> challenges the current belief that inclusion of individuals with diverse SOGIESC is too complicated for humanitarian actors. It provides clear points of action, including:

1. Ensuring the organization's policies and practices are inclusive of sexual and gender minorities.
2. Providing training to and discussing with staff about the importance of inclusion of people with diverse SOGIESC.
3. Building relationships and trust with local organizations representing sexual and gender minorities before a crisis whenever possible.
4. Where it is safe to collect information, adjust the standard categories around sex to include "other."
5. Where safe and possible for the informant, talk to persons who publicly identify as having diverse SOGIESC and include their perspectives in the

humanitarian organization's needs assessment.

6. Importantly, the toolkit cautions actors not to collect data on those with diverse SOGIESC if the actors know that these individuals are likely to experience discrimination, harassment, exclusion, and violence based on their response.

As with men, women, boys, girls, children, adolescents, older persons, the able bodied, and those experiencing disability, individuals who identify as having diverse SOGIESC have distinct and unique needs in humanitarian programming that should be prioritized.<sup>69</sup> These include the direct targeting, torture and killing by armed or criminal groups of any man who may appear 'too feminine' or women who do not conform to traditional modes of femininity<sup>70</sup>; the collapse of safe spaces where they can be themselves; the fragmenting and weakening of their networks that previously helped keep them safe; their family members turning on them, disowning them or harming them upon finding

out their non-conventional gender identity as conflict or crises ensue; and the legal precarity of their passport and presenting sex/gender identity not matching at check points and border crossing.<sup>71</sup> Nevertheless, the challenges that many diverse SOGIESC individuals face is not a reason to decide that humanitarian agencies cannot work with them. Starting with identifying and working with organizations in the country that are already working with diverse SOGIESC communities is a necessary first step to understanding needs and what is feasible on the ground, as well as the best way to collect the relevant information without putting people with diverse SOGIESC at greater risk. Given the lack of information and programming in this area, there is an urgent need to better understand the ways that diverse SOGIESC populations are being left out of humanitarian response plans and subsequently work to ensure they have the necessary access to vital resources, aid, and protection in times of conflict and crisis. More investment and guidance across donors and NGO headquarters in the area of diverse SOGIESC are greatly needed.

## Age

While not as frequently mandated as data collection and analysis on sex, the focus on age-disaggregated data is clear in the SDG goals, which require age disaggregation across only slightly fewer indicators than sex-disaggregated requirements. Age disaggregation of data is also a minimum standard in the Sphere Guidelines. However, how age data are categorized, analyzed, and translated into programming remains a serious gap, with the exception of the education and child nutrition sectors. Documentation of the analysis of age-disaggregated data was rare in our review, and the level of aggregation frequently obscured the needs of specific groups, particularly older persons.

However, a success story in age-disaggregated data has been increased attention to adolescents. Donor investment and focus has led humanitarian agencies to revise their approaches and increase emphasis on adolescents over the past decade (Box 6). A recent systematic review found that while adolescents remain a “forgotten group” during humanitarian disasters, there has been a significant uptick in reviews of interventions after 2012, indicating progress in data collection, programming, and analysis, despite the fact that significant gaps remain.<sup>72</sup>



## BOX 6

### Increased Focus on Adolescents

From 2012 to 2016, the United Kingdom Department of International Development (DFID) and Overseas Development Institute (ODI) invested in long-term programming focused on “putting young people at the heart of international development” and outlined their youth agenda, including a youth policy framework and approach to young people.<sup>73</sup> The program carried out a systemic review that found that while data were typically disaggregated by gender, rarely were any data disaggregated by age, making it difficult to distinguish between the needs of adults and those of adolescents.<sup>74</sup> The program put additional emphasis on considering adolescents not just in education programs, where significant progress has been made, but in relation to marriage and pregnancy, maternal mortality, GBV, and COVID-19. Emphasis was also put on the intersection of adolescence and disability and displacement.

A flagship of the ODI’s investment in adolescents is the Gender & Adolescence: Global Evidence project, which is a nine-year (2015–2024) mixed methods longitudinal research and evaluation study that follows 18,000 adolescences in Ethiopia, Rwanda, Bangladesh, Nepal, Jordan, and Lebanon. The research is generating evidence on “what works” to enable adolescent girls and boys to emerge from poverty.<sup>75</sup>

Their recent report looking at the intersection of disability and adolescence found the adolescents face multiple and interlinked challenges in realizing their full capabilities, including with regard to education, psychosocial well-being, bodily integrity and freedom from violence, voice and agency, economic empowerment, health, and sexual and reproductive health and nutrition.<sup>76</sup> The report also underscores the additional vulnerability of adolescent girls with disabilities. While boys in most cases are more likely to experience disabilities, girls, across most contexts are more disadvantaged by disability due to a confluence of restrictive gender norms and disability related stigma. In particular, adolescent girls with intellectual impairments are at a higher risk of experiencing sexual violence.

The findings identify significant opportunities in addressing these challenges by focusing on and providing support to caregivers of children with disabilities, but also on wider-scale support to coordinating mechanisms to facilitate joined-up, cross-sectoral programming and accountability for progress and increased financing. Thus, while challenges remain, the impact of advocacy around adolescents comes out clearly across the research agenda.

According to a government official within the UK government’s humanitarian division, there has been some progress in the collection and analysis of data on adolescents. However, how and if programming is adapted according to the analysis remains a gap:

The conversation around age and particularly around adolescents has really significantly developed in a positive direction. DFID made a huge investment around adolescent girls five to eight years ago and the conversation skyrocketed...More organizations are now involved, and not just with data but with programming, expertise, and dialogue around

adolescents. The intersection of adolescents and gender has also really taken off, and we are much further ahead now than we were five to ten years ago. In our division there is a lot of interest in funding these kinds of proposals. There is a review committee, grading, and rounds of feedback. Before a program is funded, there is a lot of oversight. Unfortunately, once the program is in implementation, there are a few reports that maybe someone reads, and then the program ends. The incentives to continue that oversight, feedback, and documentation are not built into the system. This is an area that needs improvement.<sup>77</sup>



One age group that continues to be ignored in the humanitarian sector despite their growing needs are older persons. Worldwide, older people are the fastest-growing age group. Two out of every three older people live in low- and middle-income countries in geographic locations that are at greater risk of humanitarian crises (Box 7).<sup>78</sup> Nonetheless, over the last decade since *Sex and Age Matter* was published, we have seen very little movement on the humanitarian industry addressing the needs of older people affected by crisis. Notable exceptions include the excellent work done by HelpAge International, whose leadership in this area continues to be greatly needed. Many officials we

interviewed recognized that their humanitarian agencies were leaving older people behind:

We haven't seen a lot of interest in our agency for working with older persons, so we haven't gone for a lot of funding on how to tackle this issue. But it's something we have noted and it's something that will need to be worked out if we want to make sure they have access to services. The barrier is that the older people just aren't getting services, so the data on them doesn't exist.<sup>79</sup>



## BOX 7

### Older People in the Ukraine Crisis (pre and post 2022)

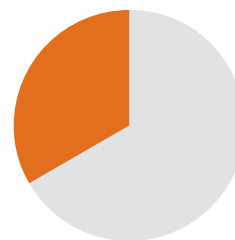
Research just prior to the 2022 ongoing war between Russia and Ukraine shows the aged and persons with disabilities in Ukraine have higher rates of poverty than<sup>80</sup> younger, abled people, making them more vulnerable during disasters. More than one-fifth of Ukraine's population (more than 9.5 million people) were over the age of 60 in 2018. More so, given the population distribution in Ukraine, the vast majority of the elderly are women, making up two-thirds of those aged over 65 and 71% of those aged above 75.<sup>81</sup>

According to HelpAge International, marginalization was already having greater effects on older individuals, especially older women, and persons with disabilities. Since 2014 and prior to the current war, older persons have constituted more than one-third of the conflict-affected population— equivalent to more than one million people.<sup>82</sup> Many of them had already fled their homes due to violence along the contact line in Donetsk and Luhansk—a line dividing government-controlled areas (GCA) from non-government-controlled areas (NGCA). The number of affected people continued to rise as the fighting impacted the mental health of the aged and persons with disabilities in Ukraine.<sup>83</sup> These populations must contend with widespread landmines and restricted access to nutrition, healthcare, housing, pensions, fuel, and public transportation.

The majority of individuals residing in and displaced from NGCA collect pensions. However, they can claim their pensions only if they are registered as internally displaced persons (IDPs) in GCA. They also had to undergo complex and discriminatory vetting<sup>84</sup> for pension verification, including home visits, physical identification in banks, and additional safeguards. This approach is riddled with liabilities and creates serious humanitarian consequences because pensions are the sole source of income for most pensioners in NGCA. If approved, administrative requirements demand the aged and persons with disabilities travel through five military checkpoints along the contact line every few months to avoid pension suspension. These individuals spend 50 to 80% of their monthly pension<sup>85</sup> on travel expenses. Consequently, many seniors are cut off from their pensions because they either are physically unable to travel to GCA or cannot afford the trip.



**Older persons have constituted more than one-third of the conflict-affected population**



Pensions are not the only reason seniors cross the contact line. They also cross to visit with family, obtain documentation, and access medical services. The many restrictions imposed on crossing result in older and persons with disabilities persons waiting at entry and exit checkpoints for extended periods of time without adequate facilities like toilets, drinking water, or shelter. Red tape often prohibits them from crossing with necessary items like medications and food, as these may not be permitted goods.

## BOX 7 Continued

People also must renew their electronic passes on regular basis if they plan to cross—a near impossibility for much of the senior population who have no computer or internet access. These conditions are detrimental to the well-being of the aged and persons with disabilities, and elderly women, creating a dire need for mental health services, psychosocial support, and lifesaving aid.<sup>86</sup>

The 2022 invasion by Russia has further exacerbated the condition of older persons. More than two million older people are at extreme risk as a result of the war in Ukraine, the majority of them being elderly women given the population distribution. Many are unable to flee due to mobility and disability issues, others are left alone without the support of family, community, or health services in the besieged areas. More so, women also make up the majority of care providers in their community, further exacerbating the burden of elderly women remaining in Ukraine.<sup>87</sup> Older persons are even more exposed to shelling and attacks as they are unable to quickly shelter from danger.<sup>88</sup> Older women are also in need of protection and assistance given that many of them are living alone and experiencing gender-based violence and abuse<sup>89</sup>.

Older persons are frequently missed in age-disaggregated data, despite the fact that they are some of the most vulnerable. This neglect is unacceptable, as older people carry the majority of the burden of disability and face physical barriers such as longer distances to distribution points, inaccessible infrastructure, and institutional barriers.<sup>90</sup> Depending on how age categories are reported, such as under or over 18, analysis could be missing the needs of older persons. Even when more precise age categories are used—18–24, 25–34, etc.—historically all individuals 65 and over are grouped together. However, the needs of someone 65 might look very different from those of someone over 75. By not collecting continuous age data and disaggregating them into specific older age cohorts, humanitarians are unable to understand how to make sure to meet their needs and assess older persons' unique vulnerabilities. According to a humanitarian official:

Older age groups are historically very lost in age disaggregation where it's all just 65 plus, so you are missing decades of the population and their specific needs... Historically agencies have stopped at age 65 but we are trying to do more grouping of that population so we can do more targeted services for that population. For example, we know that people who are older should be accessing our protection and legal case management programs and they do, but it's such a small subset and not representative of their numbers in the broader population.<sup>91</sup>

How age data are collected and categorized was one of the key challenges raised by our interviewees. There are no standard survey options/age categories, nor is the development of standardized age ranges a solution due to the different needs of different sectors. Age range use varied significantly depending on the donor requirements and the programs' different areas of focus. As a senior data manager within a leading INGO explained, "We have collected sex-disaggregated data for eight years now. But the age disaggregates are free for each project to decide based on requirements and capacity."<sup>92</sup>

The elasticity with age ranges was repeated throughout our interviews. Officials within two humanitarian INGO's explained:

We really like people to collect the actual age itself, that is our recommendation. When birthdates aren't possible, we recommend they guesstimate. But we prefer our data collection teams don't report on ranges of age. We don't like the ranges because different donors use different ranges and for our own analyses, we use different ranges for grouping...[In our organization] the child protection team has a set they prefer, and the Rule of Law team has a different set they prefer. The [women's protection team] is open, but they usually default to 18+ and under 18 years of age. However, we are trying to get away from that because it's basically meaningless.<sup>93</sup>



The challenge at the global level is the aggregation of different age categories. Youth, for example, are categorized in different ways in different countries. Age categories for an education program compared to nutrition compared to women's economic justice are very different. We have not found a way to say, "These are the age disaggregation that you need to report against in a standardized way." That is largely left up to the individual project or team to do or for individual thematic teams.<sup>94</sup>

Thus, while age data are at times collected, there needs to be guidance on how they are collected. We recommend agencies should collect data on a continuous scale, estimating where exact ages are unavailable. Depending on different sector needs, the continuous scale of age could be analyzed appropriately. However, where possible and appropriate, analysis needs to consider specific subgroups, such as older women, men and diverse SOGIESC persons. Advocacy around adolescents has led to significant focus in data collection on this subgroup which should be strengthened. A similar emphasis is now needed for older women, men and diverse SOGIESC persons, as well as for sub-groups within. Like with sex and gender analysis, most people we interviewed said their agencies collected age-disaggregated data. But on which groups of people, if it is sex- and disability- disaggregated and how its analysis is applied and leads to tangible humanitarian programming and impact remains unclear and largely undocumented.

## Disability

The claim that '15% of the world's population experiences a disability' is an often-repeated statistic.<sup>95</sup> Indeed, even in 2022 this statistic is the most referenced one, although the data come from 2004, with no available updated figures. The lack of rigorous collection and analysis of disability data is widespread in the humanitarian industry.

Using a slightly more complex metric of years lived with disability<sup>96</sup> shows that the percentage of people living with a disability has significantly increased, in part because of humanitarian crises. Global counts indicate that disabilities increased by 17% from 2007 to 2017.<sup>97</sup> On the one hand, this means improvements in premature mortality have led to an increase in older populations. On the other hand, it implies a larger population experiencing disability-related conditions. More specifically, the data from the Global Burden of Disease

report shows that from 2007 to 2017, disability related to climatic disasters increased by 156%, and conflict-related disability grew by 8%.<sup>98</sup> Thus, the presence and role of disability due to increased human exposure to climatic disaster and conflicts is a growing policy and programmatic concern for the humanitarian industry.

The following quotes from four of our interviewees reflect the wide spectrum of where the humanitarian industry is in terms of taking on disability in humanitarian response:

Right now, it's a luxury [to collect disability data]. It's not mentioned. It's an option, but it's not mentioned as a principal or standard, like age and sex are. In some types of programming like humanitarian programming you see the conversations starting to happen, but in development work we are blind to these categories.<sup>99</sup>

I do see a much stronger push to have data on disability, when my sense is that probably 10 years ago it was seen as extremely aspirational.<sup>100</sup>

We have had a gender policy in place that references the need to collect SADD. We updated that policy to include disability, which is part of us trying to achieve better gender analysis.<sup>101</sup>

We know from larger research studies that 15 to 20% of people have disabilities. So, it's not small percentage of a population. And if you're telling me, you don't know how many people have disabilities in that community, then you're telling me that there are about 20% of people whose needs you are missing. If you sign up to the humanitarian principles and you don't actually do this work on disability, then you aren't accountable at all, because you have missed about one-fifth of the population. It's about capturing all humans and understanding their needs in a crisis—this is not a revelation—you are not actually doing something better to factor in disability. Now you are going back and fixing what you weren't doing right in the first place. You aren't a hero for doing what you should have been doing for years.<sup>102</sup>

As the quotes above illustrate, humanitarian donors' and organizations' engagement on disability ranges from nonexistent, to seeing it as a means to improve SADD and gender analysis, to the rare humanitarian agencies that are mandating and holding their organization and partners accountable for including disability from humanitarian needs assessments through monitoring, evaluation, and learning.

It is only in the last few years that momentum has grown in the humanitarian industry to identify, understand, and address disability in humanitarian crises. This momentum to address disability is underway and growing due to three main factors. The first factor is the efforts that began in 2001 for multi-party, multi-stakeholder organizations to provide comparable information on disability worldwide to address the scarce and poor-quality nature of disability reporting. This consortium called for and later developed standardized indicators.<sup>103</sup> A key turning point in the emphasis on disability-disaggregated data was the launch of the "Charter on Inclusion of Persons with Disabilities in Humanitarian Action"<sup>104</sup> at the World Humanitarian Summit in May of 2016. The Charter states:

We further stress the importance of collection and analysis of disability data disaggregated by age and sex, as an important element in the design and monitoring of States' obligations, humanitarian programming and policy as a whole.<sup>105</sup>

The document acknowledges the intersectionality of disability, sex, and age:

Ensure that data collected on persons with disabilities is disaggregated by age and sex and analyzed and used on an ongoing basis to assess and advance accessibility of humanitarian services and assistance, as well as participation in policy and program design, implementation, and evaluation.<sup>106</sup>

The expanded focus on disability is also apparent in the Sphere Standards latest edition from 2018. The 2011 edition does note the importance of considering disability, however

the focus throughout the document is on SADD. There is a marked change in the 2018 edition, with a far greater emphasis on disability more generally and, importantly, the need for data disaggregated by sex, age, and disability across all programs and clusters. In addition, the 2018 Sphere Standards include a new Sphere Compendium Standard to specifically address the gap in understanding the needs, capacities, and rights of older people and people with disabilities and strengthen the accountability of humanitarian actors to this population.

Additional guidelines include the Humanitarian Inclusion Standards for Older People and People with Disabilities that go beyond a focus on data disaggregation and provide sector-specific standards<sup>107</sup> emphasizing the need to address barriers and increase the participation of people with disabilities throughout the humanitarian program cycle.<sup>108</sup> The Disability and Emergency Risk Management for Health guidelines provide guidance on addressing and collecting disability data in humanitarian health programs.<sup>109</sup> The United Nations High Commissioner for Refugees (UNHCR) 2019 guidelines provide guidelines for disability-disaggregated data for forcibly displaced populations.<sup>110</sup> And United Nations Children's Fund (UNICEF) and Humanity and Inclusion guidelines for providing humanitarian support for children experiencing disabilities<sup>111</sup> further highlight the importance of using intersectional analysis of sex and age for fully disaggregating the data.

The second factor is the prioritization of disability by donors through funding for disability inclusion in programs. These actions emphasize the inclusion of and consultation with people experiencing disability or relevant organizations, laying out disability clearly in all program documentation, collecting data on disability, and including disability-disaggregated results in the analysis and program justification. The best example is Australia's groundbreaking efforts to mainstream disability inclusion throughout all government agencies, efforts that began in 2008 (Box 8). Our research found that organizations or programs that received their funding from DFAT were more likely to prioritize disability-disaggregated data across the program cycle.

## BOX 8

### Australia's Department of Foreign Affairs and Trade (DFAT) Disability and Inclusion Mandate

While on the whole disability-disaggregated data and analysis remain a serious gap, there were exceptions, particularly when it came to organizations or projects funded by Australia's DFAT. The prioritization of disability alongside sex and age was a direct product of the mandate of DFAT for disability-inclusive development and aid as set out in Australia's *Development for All* strategy. Australia, and hence DFAT, have adopted a twin-track approach for disability-inclusive development by including people experiencing disability as participants of general development investments and targeting people experiencing disability in development initiatives designed specifically to benefit people experiencing disability. To ensure that disability is considered at all stages of the program management cycle, DFAT identifies several key priorities, including (but not limited to):

- Identifying key challenges and barriers to disability inclusion in the country/region, including through consultations with people experiencing disability and their representative organizations or organizations of people experiencing disability;
- Making disability inclusion actions clear in all program documentation, including designs, risk assessments, analyses, contracts and grant agreements, evaluation frameworks, and in any program reviews and evaluations;
- Ensuring adequate funding has been set aside (approximately 3 to 5% of the budget should be allocated specifically for ensuring the program or strategy development process is inclusive and accessible) to cover potential costs associated with ensuring people experiencing disability and their representative organizations can participate in and benefit from the program;
- Building disability inclusion into monitoring and evaluation;
- Encouraging partner governments to ascertain disability prevalence by incorporating the Washington Group questions in national censuses and administrative surveys, alongside sex disaggregation;
- Using the Washington Group questions to disaggregate program-level data by disability (and by sex where it is possible) and ensuring there are qualitative data collected, which enables processes and outcomes related to disability inclusion to be measured.<sup>112</sup>

The prioritization of disability by the funder through the inclusion and consultation with people experiencing disability or relevant organizations, laying out disability clearly in all program documentation, collecting data on disability, and including disability-disaggregated results in analysis, with clear prescriptions on the tool (the Washington Group questions) alongside allocated funding for disability inclusion and data collection was shown through our interview process to be one of the most effective ways for making sure disability was considered, included, and addressed in humanitarian data collection and programming.

The third factor is the development the Washington Group Questions (Box 9). These are a set of tools to standardize the collection of disability data that enables organizations to rapidly collect information on disability or to do a deeper dive depending on the needs of their programing. The Washington Group Questions on Disability have become the preferred data collection methodology on disability for many organizations.<sup>113</sup> The data collection relies on self-reporting focusing on severity and core functional

domains. An additional tool for capturing and analyzing disability, but at a significantly greater level of detail, is the Model Disability Survey developed by the World Health Organization (WHO).<sup>114</sup> While these are the most frequently recommended modules on disability, they do have their limitations, and considerations need to be made for each context. For example, in many humanitarian contexts, access to hearing, mobility, and seeing aids might be rare in the first place, making some of the questions less useful.

## BOX 9

### The Washington Group Short Set of Questions for Disability Statistics

Introductory phrase: The next questions ask about difficulties you may have doing certain activities because of a HEALTH PROBLEM.

1. Do you have difficulty seeing, even if wearing glasses?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
2. Do you have difficulty hearing, even if using a hearing aid?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
3. Do you have difficulty walking or climbing steps?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
4. Do you have difficulty remembering or concentrating?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
5. Do you have difficulty (with self-care such as) washing all over or dressing?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all
6. Using your usual (customary) language, do you have difficulty communicating, for example understanding or being understood?
  - a. No – no difficulty
  - b. Yes – some difficulty
  - c. Yes – a lot of difficulty
  - d. Cannot do at all

Source: <https://www.infontd.org/toolkits/wgq-washington-group-questions>



The use of the Washington Group Questions is enabling humanitarian agencies to better identify disability. An official at one of the largest humanitarian INGOs spoke about how using these questions has changed their approach:

We are underestimating the counts of persons with disabilities in the communities. We have done a revised set using the Washington Questions, and we have found three times as many persons with disabilities in the group we were working with using that method. Moving forward, the goal will be for us to get the short set of Washington Group Questions embedded

into major surveys. But for our participants where we are doing more holistic interventions, we want to use the long set of questions. In this way, when we are doing a longitudinal component, it can be part of case management so when disability issues are raised then we can actually do something about it.<sup>115</sup>

In collaboration with UNICEF, the Washington Group also developed a module to identify children aged 2 to 17 years with functional difficulties, highlighting the intersectionality of age and disability (Box 10).<sup>116</sup>

## BOX 10

### Assessment of Disability in Syria

In 2018 the Humanitarian Needs Assessment Program used the Washington Group Questions (short-set tool) alongside the UNICEF Child Functioning Module for the first time to better understand the prevalence of disability and needs of the disabled in Syria. The research found that over a quarter of individuals (ages 2 and up) experienced disability, far above the expired and frequently quoted global average of 15%. When the data were disaggregated by age, 99% of all individuals above the age of 59 had a disability. Equally important, almost one-fifth of all children under 18 reported experiencing disability. Children experiencing disability are a particularly important group of concern due to the lack of reliable data regarding their needs and the significant disruptions to their education and development caused by disability.

While males were slightly more likely to report experiencing a disability, women with disabilities face increased barriers to accessing livelihoods and obtaining sufficient income. For example, females with disabilities are 84 percent less likely, compared to males with disabilities, to be employed. Nearly half (43 percent) of female headed households have disabilities, suggesting a double burden of gender and disabilities. More so, disabled female heads compromise the majority of the widowed population with 1 in 5 females with disabilities above the age of 17 being widowed, while males with disabilities are significantly more likely to be married. Some of these disparities are attributed to the high rates of male mortality across Syria. Females with disabilities who are not married face increased social exclusion compounding pre-existing vulnerabilities for them and their household.

The report also used household-level analysis, finding more than half of all households in some regions having at least one person with disabilities, with female headed households faring the worst. Disability inside a household has a direct impact on the resilience of all members in that household and their ability to cope with a humanitarian crisis and thus needs to be considered along with individual-level data.<sup>117</sup> Based in part on the findings of this assessment, UNICEF Syria has now implemented a cash transfer program focused on children experiencing disabilities.<sup>118</sup> The impact and monitoring, evaluation, and learning (MEL) of this program were not reported at the time of publication of this report.



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The findings from the Syria case study above highlight the importance of incorporating disability data collection, disaggregation and analysis, alongside intersectional analysis considering age and sex. The staggering prevalence of disability in Syria and how it interacts with everyday needs across sex, gender and age groups is critical for addressing needs in an intersectional way. Individual exposure and vulnerability to a humanitarian crisis is intrinsically related to age, sex, and disability status. The findings make it evident that the success of humanitarian programs depends on inclusion mainstreaming throughout all programs, including the use of the Washington Group

Questions and, for children, the UNICEF Child Functioning Module for Assessment of Disability, to better assess the prevalence and needs of persons experiencing disability.

We are at the beginning of this work, and the need to document, distribute, and share lessons learned and best practice is essential to move policy and practice forward. The pressure of national and international disability movements, and the availability of these tools, coupled with donor engagement, has jump-started humanitarian agencies to make sure disability is considered, included, and addressed in humanitarian data collection and programming (Box 11).<sup>119</sup>

## BOX 11

### Disability, Intersectionality and Distribution in Afghanistan

Until 2020, the existing practice in Afghanistan was to run a distribution or program and hope that persons with disabilities were able to benefit from it. There was no specific focus on individuals experiencing disability, so if the person did not meet a requirement of being an internally displaced person, a refugee, or a member of another existing target group, they would be excluded. This approach resulted in significant barriers to access of services by persons with disabilities. Considering that Afghanistan has been in a continuous series of wars since 1978, the burden of disability is great and requires a special focus and additional facilities to improve humanitarian access and targeting. In addition, given the invisibility of women in Afghan society, information on women experiencing disability was almost completely absent.

At the beginning of 2021, disability-disaggregated data were required for project implementation by a group of donors in Afghanistan. Information was specifically required to show the number of people experiencing disability reached by a distribution or program and how the distribution or program targeted people experiencing disability. Organizations were also required to ensure that the humanitarian teams improved access for people experiencing disability to their services, and to document how the distribution or programs were adjusted to meet the needs of the blind, deaf, and individuals with mobility problems. The review process at headquarters was strong and well-coordinated, involving disability expertise and much back and forth between coordinators and partners doing the implementing.

However, the field teams carrying out the distribution or programs did not have the appropriate support in terms of training around disability and disability data collection that were aligned with the new requirements. Therefore, they simply did not have the ability to generate the requested information back to headquarters. Nor were they able to generate clear documentation on how programs were adjusted to meet the needs of people experiencing different kinds of disabilities.

To remedy this incongruence, the donors made multiple changes to the team running the collective fund. First, they invested in a dedicated person to work on disability. This disability specialist set up the strategy, improved collection of data on individuals experiencing a disability, and monitored and communicated directly with partner organizations that might not be reporting these data. Second, all monitoring tools were revised to include the short set of Washington Group Questions on disability, with other questions integrated as necessary.

Third, the collection of disability-disaggregated data was mandated across all projects and specific targets set for number of people experiencing disability reached. Fourth, field teams were sent out to talk to people experiencing disabilities to better understand how their needs might not have been met and what additional support they require, which was then fed back to the implementing partner.<sup>120</sup>

This is only the start of the process, as field teams still require additional support in capacity building, data management, and documentation of how programs are being adjusted. This case study clearly illustrates that setting disability-related targets needs to be directly accompanied with significant support to the field teams to make sure headquarter and donor requests are appropriately implemented.



Almost no humanitarian organization we reviewed had disability specialists on their staff. This factor plays a significant role in the neglect of this population:

There were some concerns about what questions we would put in on disability because of the “do no harm principle.” We didn’t want to raise issues if we couldn’t address them. We didn’t want to find too many people experiencing disability because we didn’t know what to do with them.<sup>121</sup>

Our interviewees stressed that partnering with external disability organizations and movements, especially within the countries they were working in, was essential to informing and enabling their work on disability in crises. Local and national disability groups offer the expertise, experience, and guidance needed by humanitarian agencies that currently lack capacity in this area.

Some organizations are also beginning to adopt operational standards and guidance on assessing disability and inclusion. For example, DG ECHO now requires a disability inclusion provision in all its funding of humanitarian assistance.<sup>122</sup>

## Intersectionality

The need to understand and respond to different forms of identity and social categories including sex, diverse SOGIESC, age, and disability inevitably leads to questions around intersectionality and the need for intersectional analysis. Intersectionality “is the complex, cumulative way in which the effects of multiple forms of discrimination (such as sexism, racism, classism, ableism, and homophobia) combine, overlap, or intersect, especially in the experiences of marginalized individuals or groups.”<sup>123</sup>

Disaggregating data by the many identities that shape individuals’ and groups’ lives during humanitarian crises requires first paying attention to different social identity categories with the goal of then bringing them together in our analysis to better understand the whole of what is being experienced. Intersectional analysis probes “beneath the single identity to discover other identities that may be present and contribute to the situation of disadvantage.”<sup>124</sup> Notably, one should not assume the same effect or constellation each time. Therefore, the investigation of the specific social, political, and economic processes involved in each historical instance is important.<sup>125</sup> An excellent example is found in the intersectional analysis of the Beirut Port Explosion and the resulting influence of its findings (Box 12).





## BOX 12

### The August 2020 Beirut Port Explosion: An Intersectional Examination

In August of 2020, the Port of Beirut in Beirut Lebanon exploded taking the lives of 191 persons (120 males, 58 females, and 13 unspecified), wounding at least 6,500, and displacing approximately 300,000 people. This port explosion was compounding an already tenuous domestic situation with a crippling economic crisis, increasing food prices and food insecurity, global and domestic fallout from COVID-19, and worsening rates of gender inequality.<sup>126</sup> In the midst of these overlapping crises UN Women, CARE, United Nations Economic and Social Commission for Western Asia (UN ESCWA), ABAAD – Resource Center for Gender Equality in Lebanon, and UNFPA undertook a Rapid Intersectional Gender Analysis (RGA) that had two key objectives, both of which were met:

- To identify and analyze differences in how the Beirut explosion impacted women, girls, men, boys, and gender minorities, including their intersectional identities: LGBTIQ+ persons, older people, persons with disabilities, refugees, and migrants (within the broader context of the COVID-19 pandemic and economic crisis);
- To inform the Beirut Explosion humanitarian response and recovery interventions with the voices of women, LGBTIQ+ persons, and other marginalized people and groups.<sup>127</sup>

The RGA found a wide range of impacts including women's demographics and representation, health, shelter, food security, and livelihoods. The individuals impacted by the ongoing crises in the country and the subsequent port explosion come from diverse SOGIESC, ages, and abilities. Intersecting identities impacted people's access to medical care, shelter, economic recovery, and additional forms of relief and assistance. For example, 8% of the population living in the blast radius were older women living alone who struggled to access in-person relief and assistance, were less likely to have savings or a pension to assist them in recovering from the blast, and were significantly more likely to have a disability affecting their mobility.<sup>128</sup> Another example is the heightened risk that individuals without proper documentation faced in accessing and receiving medical care after the blast; migrant workers, Syrian refugees, and trans women and men in particular expressed that they did not receive full care due to affordability, issues with documentation, and discrimination.<sup>129</sup> These two examples highlight the value of gender and intersectional analysis to inform humanitarian response.

The RGA recommendations focused on informing programming and policies to improve reach and access for all individuals affected by the Beirut Port Explosion. Common themes included: develop partnerships with local organizations for more sustainable and long-term care; employ rigorous methodological tools such as utilize qualitative data in response, feminist research methodology, and continuous gender analysis throughout the crisis and response; include gender sensitive training for humanitarian workers, particularly those who work on issues around GBV.

The RGA's findings on gender, social inclusion, diverse SOGIESC, disabled people and migrants were cited throughout the Lebanon Reform and Recovery Framework, which shaped the EU's, World Bank's and the UN's financing and approach for recovery and humanitarian efforts. The findings also fed into the main consultative committee comprised of Lebanese CSOs, the Government of Lebanon, the EU, the World Bank, and the UN. Women's rights and disability rights' representatives are members of this decision-making committee, which the Prime Minister of Lebanon also attends. The RGA also informed OCHA's Flash Appeal and Lebanon Humanitarian Fund (a pooled fund overseen by OCHA for local NGOs), with an emphasis on responding to the findings regarding the experiences and resulting needs of people experiencing disabilities, older people, and people with diverse SOGIESC.<sup>130</sup>

If done correctly, there is real analytical power in applying an intersectional lens to sex-, age-, and disability-disaggregated data. To illustrate, if you look at research on primary school enrollment in war affected northern Uganda, you may find almost equal percentages of girls and boys enrolled in

the lower grades. But dig a bit deeper into actual regular attendance, and disaggregate by a school child's sex, age, and experience of disability, and a vastly different picture emerges (Box 13).

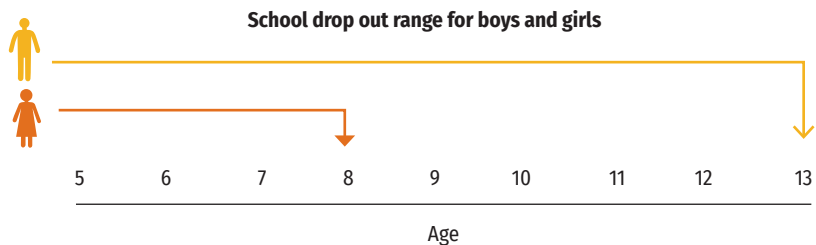
### BOX 13

## Enrollment and Attendance at School in northern Uganda by Sex, Age, and Disability: An Intersectional Analysis<sup>131</sup>

Almost three decades of armed conflict in northern Uganda has significantly disrupted children and young people's access to education. More than a decade after the cessation of fighting, the long-lasting negative impact on educational attainment remains visible. There are too few classrooms and too many students per teacher. Qualified teachers show up infrequently to teach. Overall, the educational quality is extremely poor. More than half of the students that graduate from primary school are illiterate.<sup>132</sup> These factors affect all students to different degrees.

However, representative data from Acholi and Lango sub-region in Uganda collected as part of longitudinal study by the Secure Livelihoods Research Consortium in 2013, 2015, and 2018 found not only population-level impacts on education of the three decades of conflict but also significant differences by age, sex, and experience of war wounding.

The research found that primary school attendance from 2013 through 2018 declined by approximately 20%. Girls had the highest rates of school dropout or failure to regularly attend school across upper primary, secondary, and tertiary education. For boys the drop-off occurred around the age of 13. For girls, enrollment and attendance starts to steeply decline after age 8, so interventions and incentives to stay in school must start very early for girls in particular.



More so, in northern Uganda, the drop in enrollment for girls appears, in part, to be related to livelihood diversification. The research found that in years of good rainfall and harvest, households appear to be maximizing girls' labor and taking them out of school to take advantage of increase livelihood opportunities and/or coping with post-conflict volatility by taking on additional income sources.

The authors found that both girls and boys who experienced war injuries, abduction, forced recruitment, or resulting ill health were also significantly less likely to continue with their education. Disabled girls were the least likely group to attend school. The use of intersectional data analysis in this study points to the clear need for policies and programs to consider the different enrollment status and drivers of school attendance across sex and age, as well as the role of the long-lasting, debilitating physical and mental impact of conflict on school-age children.

While intersectional analysis includes considerations for race, ethnicity, livelihoods, socioeconomic status, and many other factors, from this study we limited our interview questions to the intersectionality of sex, age, disability, and diverse SOGIESC with the understanding that intersectional identities are more complex.

Smart intersectional analysis is a complex undertaking. We found that most organization did not engage in intersection analysis, and they rarely go beyond one variable-level disaggregation. Given that we already find limitations in disaggregated analysis of sex, gender, diverse SOGIESC and disability, this finding is not surprising. Intersectional analysis was perceived by some as simply asking for too much:

Unless you are very specific on [intersectional analysis], it is something that is perceived as more work.<sup>133</sup>

Organizations were clear that while intersectional analysis was acknowledged and valued its application was limited, as illustrated by quotes from three different officials at international humanitarian organizations:

We are pretty good at looking at how sex intersects but I wouldn't say we are good at looking at three or more things at once...When it comes to doing deep intersectional analysis with [sex, disability, age], I can't think of a good example when we have done that.<sup>134</sup>

I can't think of any examples where all three elements—sex, age, disability—were looked at.<sup>135</sup>

There are so many of these intersecting potential lenses of analysis of exclusion so you can't work on all of them in all places equally. You have to make decisions on levels of exclusion, resources, where do we add value, what do we have legitimacy to work on, what is legal to work on.<sup>136</sup>



Given the complexity of taking an intersectional lens and choosing from across a multitude of indicators, interviewees said that they need additional, country- and program-specific guidance on what intersectional data to collect and what analysis to conduct. Simply telling the organization or analyst to do more intersectional analysis, without providing data and specifying what and how, is not enough and is not useful, as two of our interviewees pointed out:

The intersectionality aspect could be so much stronger at [name of organization] with more guidance on how to do it. It is used as a throwaway—be intersectional in your work—but how you use it and then take it forward, and guidance on how to do that is needed because now it feels more performative. If there is not more guidance it will not be carried through.<sup>137</sup>

We have not gone the extra mile in being trained or having a training package speaking to aspects of intersectionality data management.<sup>138</sup>

A major concern of the interviewees was data use. Even if guidance on intersectional analysis is provided along with capacity to conduct appropriate intersectional analysis, will that effort translate into it being used in HNOs, response plans and or programming? According to the interviewees, the greatest investment is needed in how to gather and use all the data and analysis conducted to improve programming:

We need to have the necessary capacity to address the intersectional analysis that is being requested...It's nice to say we want to be intersectional but if we are going to go down that route the humanitarian community needs to be able to back that up. We do not have a cadre of disability, LGBT experts, decolonizing experts. How do we back up the data that has been collected?"<sup>139</sup>

When it came to intersectional analysis, not all the interviewees agreed that it was necessary, either due to the additional time constraints or the inability of the organization to follow through on the analysis.

Among those who agreed that it should be done, they said they needed additional guidelines on how to do it, what

variables to focus on, implications for sample size, etc. If the humanitarian community is going to seriously engage in intersectional analysis, it means having the right experts in the right places who can address and enforce a variety of issues regarding social inclusion—gender, older persons, adolescents, persons with disabilities, diverse SOGIESC, and as needed religion, race, socioeconomic status, religion and more. Serious engagement in intersectional analysis also means those experts need to be working together in a non-siloed approach to identify and document clear guidelines to enable the appropriate, context- and program-specific intersectional analysis that is required. A focus on intersectionality can be very useful and requires funding for additional staff and expertise and clear pathways to allow for this level of cooperative work and analysis to translate into humanitarian cycle programming.

### Data Management, Analysis, and Use

Data collection, management, analysis, and use requires a considerable time investment for both field staff and the individuals they are interviewing. While a key step to initial data collection and analysis involves the availability of simple guidelines and occasionally external expertise, the management, sharing, and use of that data are equally critical and require additional support, funding, and dedicated positions. Frequently after the initial investment in data collection, the data themselves are stored on a shelf or someone's personal computer and do not see the light of day again. This is a huge waste of everyone's time and resources, resulting in repetitive data collection and limited learning.

The humanitarian community does not always need to collect more data. Frequently, multiple humanitarian actors working in the same area collect repetitive information that is never shared among themselves. The analysis of secondary data is a first step in any analysis, with primary data filling gaps or providing additional real-time information. In addition, publicly available secondary data allow for analysis by outside expertise, including comparisons across time and contexts for better program implementation and evaluation:

In places we don't have good data management or coordination between programs, we don't share information. We have to re-collect the data so it's a burden on the community and people don't feel comfortable giving the same information again and again.<sup>140</sup>



Data management system is critical because in most cases we are working in protracted crisis. If we have good database management system, it's more about updating information than collecting it again and again.<sup>141</sup>

However, data management is time consuming and requires specific expertise in making sure the data are clean, properly labeled, standardized across programs and sectors. Ensuring data meet ethical standards, are correctly translated, and are collected safely requires tech support and significant staff time. As one interviewee put it:

The commitment and passion are there, but practically it's really difficult to manage all the disaggregation with our limited resources.<sup>142</sup>

Given the data needs in the protection sector, several interviewees identified learning from the protection sector and having a dedicated person whose responsibility is data management, analysis, and use. We agree that this type of role needs to be expanded or created to cover all sectors. Along with a data role, there needs to be an industry-wide effort to allow for the creation and support of data dashboards, so that anonymized data are internally or publicly available and can be analyzed across programs, sectors, populations, and years by headquarters and external stakeholders, including local actors.

An excellent example of a robust information management system is the Gender-Based Violence Information Management System (GBV IMS). GBV IMS is an initiative that was launched in 2007 by United Nations Population Fund (UNFPA), UNHCR, and the International Rescue Committee (IRC) to store, analyze, and share GBV-related data generated through service delivery. However, this system took a considerable number of resources, including training, ongoing roll-out, trouble shooting, and technical support. More so, such an investment cannot be one-off, and the GBV IMS requires consistent upkeep:

There was a GBV IMS committee, years of pilot testing, global technical advisors who were GBV experts and data experts training people on the system. It's a system owned by case managers in the field that specifically captures info that then they use for program improvements and program

adaption. Then there is a whole process around anonymizing the data so it could be compiled at a national or global level to figure out aggregated trends around violence reports, survivors.<sup>143</sup>

The lift is heavy but the impact of GBV IMS is significant. GBV IMS is partially responsible for the humanitarian community's pivoted towards adolescent girls, given the data coming out of West Africa on adolescent girls and GBV. GBV IMS is also credited with helping to make the shift from an exclusive focus on GBV to intimate partner violence (IPV) during armed conflict and crises. The GBV IMS system has also informed and driven advocacy, programing, and policy and was consistently reported across our interviews as a critical tool for people directly doing the implementation, as well as headquarters. Thus, while a significant investment in resources, time, and money went into creating the GBV IMS, this long-term investment means the humanitarian community has a rich resource to shape planning and response.

An important conversation happening around the collection of SADD is how many data are too many. One of the primary complaints raised in our interviews was that there was massive amount of required and suggested data to be collected. Then nothing gets done with them, so collecting them is a waste of time, capacity, and resources:

Now everyone wants SADD because of the SDGs saying that all data should be disaggregated. But nobody does anything with this data so it's a huge effort that takes a lot of effort for participants and takes away from the capability of the team.<sup>144</sup>

The collection of data without any clear direction on how to analyze and utilize them is a massive time investment for field staff and unfairly burdensome for participants. An overemphasis on data collection without accounting for additional staff and capacity needs to make use of them to inform HNOs, response plans, programing and monitoring, evaluation and learning means that the end-use of the data is not happening because everyone is over- extended:

Everyone wants the data—and everyone has to report the data, so you then have no energy or capacity in the end.<sup>145</sup>



A key gap in using disaggregated data and analysis identified across our interviews was documentation of what worked and how the findings were translated into program amendments or implementation:

I would say broadly country officers who are implementing programs really rely on tools, guidance notes, reports—they are overstretched in terms of implementation. They are always looking for more guidance. In the humanitarian community in general—we are facing it with our shelter team—they are hesitant to implement the women-centered approach because they say they do not know how it works or they do not have time. The humanitarian sector in general needs more examples and programming and funding that enables a really intentional effort to do these kinds of approaches to use sex- and age-disaggregated data.<sup>146</sup>

In some cases, the interviewees said that the data did lead to meaningful program change, but it was never documented because no one had the time, capacity, or funding to document how data were translated into programming:

There are reams of learning that have *not* been published but have been used to make the [program name] really specific on how to work with the girls.<sup>147</sup>

When we inquired why documentation was absent, we got a consistently similar response. Documentation of impact was not a requirement, and when it was done it was due to the will of one individual:

Some country offices are good, and they are doing that, but it is not a requirement...I always tell people it's about the individual—if there is a good person in a country office, they will do that but if they leave, the system won't necessarily work in the same way.<sup>148</sup>

Thus, even when interviewees broadly said that data were used to adjust programming, few could point us to any documentation or evidence of that use. Without proper documentation and given the high turnover in the humanitarian field, it is impossible to count on institutional memory alone. The humanitarian community needs clear, documented evidence on how and range of disaggregated data and analyses have been used, the effect on diverse crises affected populations, and how lessons learned can be translated into change in humanitarian programming cycles to improve long-term learning and results.

## Conclusion

As is evident from the workshop, key informant interviews, and literature review, the humanitarian community has made some positive strides towards the collection, analysis, and use of disaggregated data since the first *Sex and Age Matter* report. The progress comes mostly in the form of improved international standards and frameworks, as in the IASC 2017 Gender Equality and the Empowerment of Women and Girls in Humanitarian Action Policy, the SDGs and Sphere Standards for the collection and analysis of sex-, age-, and (to a lesser extent) disability-disaggregated data. The availability of simple, effective, and utilized guidelines and instruments such as the RGA and Washington Group Questions among others has enabled important steps forward.

The gaps that remain are due to the need for accountability mechanisms, and additional funding, expertise, time, and guidelines to make sure that sex, age, disability, and diverse SOGIESC are considered, and gender and intersectional analysis is conducted, across humanitarian data collection and programs.

Some important progress has been made around sex-disaggregated data and use of gender analysis, although as this chapter demonstrated there is a long way to go to meet the intent of the standards to promote gender equity. There has also been increased collection of data on age and focus on adolescence, but older people continue to be neglected. There is evolving consideration for people experiencing disability and some effective tools to help enable data collection and analysis. Overall, we found a lack of investment and thinking around inclusion of diverse SOGIESC individuals in humanitarian programming cycles.







## CHAPTER 3 Case Studies

In this chapter, we take a deeper dive into two case studies to understand the availability, value, and gaps in SADD, and gender and intersectional analysis to inform humanitarian response. First, we look how the use of gender and age analysis in understanding the Ebola outbreak highlights how women, girls, men, and boys face very different vulnerabilities when it comes to infection, transmission, and impact. Next, we look at data on disability from war-affected northern Uganda to show how critical disability data with consideration for sex and age are to understanding the impact of conflict and the different needs of people experiencing disability and their households. Following each case study, we make recommendations for the humanitarian community in light of the research and existing guidelines.

### CASE STUDY 1

#### Understanding Ebola Using SADD and Gender Analysis

Between March 2014 and June 2016, the West African nations of Guinea, Liberia, and Sierra Leone experienced the largest Ebola virus outbreak recorded in human history. The disease infected tens of thousands of people until mid-2015 when an organized, high-level response by international organizations and countries around the world began to slow the speed of new infections.<sup>149</sup> In total, 28,000 people were infected, and approximately 11,000 deaths were officially recorded.<sup>150</sup> The true numbers of the infected and dead are likely higher.

The harmful impact on the countries' health, educational, and economic systems will take years to recover from. An application of gender analysis, review of SADD, and an intersectional approach illustrates how Ebola and its long-lasting consequences affected women and men, and adolescent girls and boys very differently across the spectrum of infection, transmission, income, maternal health, GBV, pregnancy, fetal complications, childbirth, and community stigma.

During the 2014–2016 Ebola epidemic in West Africa, the WHO found no significant sex differences in the numbers of cases of human Ebola infections in West Africa. However, reports from UNICEF and health workers suggest that quantitative data did not capture the full picture of the risks and effects of the Ebola crisis.<sup>151</sup> Indeed, reliable SADD on cases and fatalities were conspicuously absent in the early stages of the 2014 outbreak, making an accurate sex and age analysis difficult.<sup>152</sup>

A sex, age, gender, and intersectional analysis of the socio-cultural and economic circumstances in the regions where Ebola outbreaks are most common provide important information about who is at risk and how during an outbreak. Ebola outbreaks have been directly linked to contact with wild animal carcasses during hunting activities.<sup>153</sup> The majority of hunters of wild bushmeat and animals are typically men from local populations.<sup>154</sup> However, when it comes to transmission of the disease which is transmitted through contact with infected bodily fluids, women have greater exposure given their role in caretaking.



Ebola presents a unique and significant threat to pregnant women, who when infected have higher mortality rates and experience fetal complications. Maternal death rates range from 74–100%, and fetal losses reach nearly 100%.<sup>155</sup><sup>156</sup> Pregnant women have also been denied medical care due to fears from health workers about contact with the patients' bodily fluids during an outbreak.<sup>157</sup> <sup>158</sup>

The Ebola epidemic sparked the increase in GBV and teen pregnancies among girls in Liberia, Guinea, and Sierra Leone. During the Ebola epidemic, the teen pregnancy rate in Sierra Leone increased by a staggering 40 to 65% depending on the region of the country, and an additional 14,000 more girls became pregnant.<sup>159</sup> School closures<sup>160</sup> and public health measures to try to slow the spread of Ebola included quarantines. In Liberia, entire slums were confined, with no inhabitants able to leave and in some cases, security guards enforcing quarantines that locked women and girls into spaces with male strangers, neighbors, and family members.<sup>161</sup> In a study by Save the Children, almost all of the 617 girls they interviewed in Sierra Leone reported violent and sexual attacks against girls quarantined in their homes.<sup>162</sup>

Gender analysis with consideration for age disaggregation in global health policy is critical in not only reducing infectious spread but also in understanding what programs need to be in place during and after an outbreak to remedy long-term impacts on men, women, boys, and girls.

However, the gender and age consequences across age groups remain poorly addressed since the 2014–2016 outbreak, with limited collection, analysis, and use of SADD.<sup>163</sup> The WHO Ebola Response Roadmap, World Bank country reports, and the Global Health Security Agenda did not include systematic considerations of SADD indicators in monitoring frameworks. Indeed, efforts to bolster gender-responsive health services solely focused on formal health workers, despite the fact that the majority of developing countries rely heavily on the informal economy and unpaid or volunteer female caregivers.<sup>164</sup> From the above analysis it is clear how vital utilizing SADD is in a crisis. The Ebola epidemic and the subsequent humanitarian response is not a one-size-fits-all situation. The experiences and needs of individuals varied dramatically based on sex and age and, most importantly, on the intersectionality of the two.

## The Way Forward

While the above case study specifically focuses on Ebola, it has wider implications for how we look at zoonotic spillover in humanitarian contexts. Zoonotic spillover has resulted in the pandemic of COVID-19 (plus its variants) that has engulfed the world.<sup>165</sup> The numbers as of August 2022 are staggering: a conservatively estimated 575,000,000 reported cases and 6,400,000 deaths.<sup>166</sup> Worldwide, in the first year of the pandemic, the lack of sex-, age-, class-, race-, and disability-disaggregated data and intersectional analysis by countries' leading national health agencies on COVID-19 led to dangerous and sometimes fatal gaps in knowledge of and response to the zoonotic spillover public health emergency.<sup>167</sup>

In light of the ongoing COVID-19 pandemic, humanitarian agencies have had to reassess and reconfigure almost all field programming. Current and emerging zoonotic pandemics now occupy center space in humanitarian policy, planning, and funding efforts, and will continue to do so for the foreseeable future. Yet, with the rare exceptions, collective knowledge on the intersectional drivers, risks, and impacts of zoonotic pandemics is extremely weak.

Guidance on SADD, and gender and intersectional analysis around zoonotic diseases, and infectious diseases more generally, is mixed. For example, the Global HRP for COVID-19 notes that data collection and analysis is a worrying gap, without providing recommendations on data disaggregation.<sup>168</sup> The broader guidance note on Protection of Children during Infectious Disease Outbreaks is better and calls for SADD, with consideration for disability, to identify individuals with protection concerns.<sup>169</sup> The WHO guidance calls for data disaggregated by sex, with a short section on older persons, and only considers disability as a consequence of infectious disease and not as a source of risk.<sup>170</sup> On the other hand, USAID's Gender and COVID-19 guidance acknowledges the lack of disaggregated data (across sex, age, race, disability, income, and pregnancy status) as a problem and consistently calls for and provides guidelines for an intersectional lens.<sup>171</sup>

The humanitarian community needs clearer and consistent guidelines on SADD and intersectional analysis to improve our understanding of the epidemiology and outcomes of emerging pathogenic spillover. These same data and

analysis of them can aid in the reduction of risk and increase community participation in spillover prevention, control, and management. We also need this information to help stakeholders understand and address the specific perceptions, risks, consequences, and impacts that different groups of people face from zoonotic disease spillover, amplification, and spread. Finally, this information can help the humanitarian community strengthen capacities to develop, analyze, validate, and implement gender equality, responsive, and culturally appropriate interventions within the context of addressing zoonotic spillover that are relevant to men, women, boys, girls, and those with diverse SOGIESC.

The gendered, social, cultural, and economic determinants of human lives, the societies people live in, and their ability to respond and act all affect their risk of spillover exposure, their health-seeking behavior, and the preventive and response measures that should be implemented. Recognizing how emerging zoonotic outbreaks affect diverse people differently, and subsequently how to target relief and response for those different groups, is a vital step toward understanding the primary and secondary drivers and effects of zoonotic spillover on people and communities. Greater attention needs to be paid to ensuring the collection, analysis, and use of gender-, age-, disability-, and relevant intersectional-disaggregated data, and the use of gender and intersectional analysis to understand drivers, risks, and impacts of zoonotic spillover and to shape successful national and global response plans.





## CASE STUDY 2

### Disability, Conflict, and Recovery in Northern Uganda

In this case study we use sex, age, disability disaggregated data and gender analysis to present the burden and impact on individuals and households in the two sub-regions of northern Uganda—Acholi and Lango—that were most affected by the 20+ year war between the Lord’s Resistance Army and the Government of Uganda through its Uganda People’s Defense Force. Both parties committed serious violations and abuses of international law in a conflict that ended in 2007 in Uganda. The research findings we present here come from two studies. One is a representative study of the Acholi and Lango populations as part of the Secure Livelihoods Research Consortium.<sup>172</sup> The second is a study carried out by the Secure Livelihoods Research team in Uganda for the International Criminal Court (ICC) that focused specifically on the victims of three massacres committed by Dominic Ongwen<sup>173</sup> in 2004. The findings were then presented at the *Prosecutor vs. Ongwen* trial and were considered by the judges, prosecutor, and victims’ lawyers

to inform discussions regarding criminal responsibility and reparations for victims and their communities.<sup>174</sup> The case study shows how not only the magnitude of disability in post-conflict-affected contexts but also how paying attention to disability-disaggregated data across all outcome indicators shows worse outcomes for households with disabled members and the need for tailored programming.

Across both studies, disability was defined according to the Uganda’s Persons with Disabilities Act as a substantial, functional limitation of daily life activities caused by physical, mental, or emotional impairment and environmental barriers that result in limiting a person’s participation.<sup>175</sup> Thus, both physical and mental disability is captured as a characteristic on the individual level that “affects their ability to work a lot” or results in the individual reporting that they “cannot work at all.”

Disability had a broad impact on the population of Acholi and Lango, whether they experienced war crimes or not. 21% of the general population reported a disability, and half of those with a disability reported the disability negatively

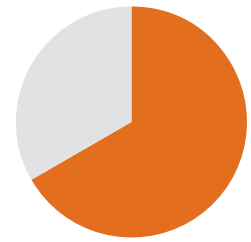


affected their livelihoods. In other words, 10% of the general conflict-affected population has a disability that affects their ability to make a living.<sup>176</sup> Experiencing disability not only impacted the types of livelihoods an individual could take part in, but also the number of livelihood activities a household or individual could engage in. A sub-sample survey of households with war-wounded members shows that, on average, injured individuals went from 4.5 livelihood activities prior to the injury to 2.5 activities afterward. Individuals with disabilities also reported significantly lower household wealth (measured in asset ownership) and higher food insecurity. More so, the greater the proportion of persons with disabilities in a household, the worse the entire household's food insecurity.

Households with at least one war-disabled member were significantly more likely to use a larger number of coping strategies. The greater the proportion of members in the household with disabilities, the more coping strategies the household reported using. Additionally, disability was strongly correlated to the sex of the household head, with female household heads significantly more likely to report a disability. The higher odds of a female household head being disabled is likely due to the disproportionate mortality for men compared to women in the Uganda conflict, thus leaving behind more women and female heads with disabilities. Similarly, the older the household head, the significantly more likely it is that they experienced disability.<sup>177</sup> These findings further indicate the importance of analyzing data with an intersectional lens across sex, age, and disability.

While disability in northern Uganda was associated with significantly worse outcomes, it did not necessarily translate into greater access to services. Households with a war-related disabled individual were no more likely to receive livelihood support from the government or NGOs than households that did not report a household member with a disability. And while households with a war-related person with a disability were significantly more likely to receive social protection services from the government or NGOs, only seven person of households with a war-related disability actually did, and most of the support was one-off.<sup>178</sup>

**two-thirds of the surviving massacre-affected population reported a disability.**



In the study on the massacres carried out at the orders of Lord's Resistance Army Commander Dominic Ongwen, two-thirds of the surviving massacre-affected population reported a disability. For more than half of those individuals (or 38% of the massacre-affected population), their disability "affects their ability to work a lot" or they "cannot work at all."<sup>179</sup> And while significant differences in disability were observed by age group, disability was present in all age groups.

Disability not only affects the individual. It also affects the entire household. An individual affected by the Ongwen massacres reported, on average, two people experiencing disability per household. This number is double the number of people experiencing disability per household for the general war-affected population in the region. The high level of disability in households that were affected by the Ongwen massacres directly translates into a high dependency ratio. Indeed, a stunning 70% of household members among the Ongwen massacre-affected population were described as dependents, which has profoundly negative implications for household livelihoods and access to resources more broadly.<sup>180</sup>

Similar to the findings on the general war-affected disabled population, the massacre-affected population was no more or less likely to receive either livelihood or social protection services from government or NGO sources. Notably, there was no relationship between the experience of disability or number of disabilities and greater access to support services.<sup>181</sup> Thus, while the data clearly indicate a greater burden on disabled individuals and households that necessitates access to government and humanitarian services, those services were not distributed or targeted accordingly, again highlighting the gap between what the data reveal and how humanitarian assistance in the area was designed and carried out – in a way that failed to recognize and respond to the most vulnerable and at need households.



## The Way Forward

There has been important progress in the emphasis on disability-disaggregated data across a host of guidelines, standards, and tools. However, this progress has not been unilaterally reflected in data collection, analysis, implementation, and strategy around humanitarian needs planning. Thus, the humanitarian sector has a real opportunity for collective progress on addressing sex, age, gender, and disability in humanitarian crises.

People experiencing disabilities are key actors and not passive participants in a humanitarian crisis. The experience and knowledge of persons with disabilities are essential for delivering an inclusive humanitarian response. Thus, programming needs to prioritize working with persons with disabilities and inclusion within their own staffing. This shift is in line with a broader priority of accountability to affected populations and is closely linked to the localization agenda.

In order to collect better disability-disaggregated data, organizations need clear guidelines for data interpretation and program adaptation, complemented by appropriate training on the guidelines, and additional funding. The Washington Group Questions are an important step, as they provide a clear survey tool for the collection of disability-disaggregated data. Learning from the progress on the RGA, additional *simple* guidelines are necessary for how that data should be analyzed and interpreted for program adaptation.

Just as we can borrow a lot of our learning on how to improve the collection, analysis, and program adaptation on disability from the progress made around collection of gender data and gender analysis in the past four decades, we can also turn to and learn from the positive examples within the donor community, specifically Australia's DFAT mandate and requirements on disability. The requirements of the donor is usually the first framework for data collection. Thus, an investment and understanding by donors, complemented with suitable funding and expertise, are a critical step in the prioritization of disability in the humanitarian sector. What is needed is a system-wide push, from the donor level and headquarters, to mandate disability data collection alongside sex and age. Funding for the development and testing of tools and guidelines and an increase in headquarters and field staff who can analyze and program around disability inclusion, including experts on disability, are also needed.

Another important consideration for disability-disaggregated data is the intersectionality of disability with sex, age, and other characteristics. As the Sphere Standards highlight:

To be young or old, a woman or girl, a person with a disability or of a minority ethnicity does not in itself make an individual universally vulnerable. Rather, it is the interplay of factors in a given context that can strengthen capacities, build resilience, or undermine access to assistance for any individual or group.<sup>182</sup>





Most of the guidelines and standards on disability emphasize disability-disaggregated data clearly and thoroughly. However, while considerations for disaggregation of that disability data by sex and age are also included, they are frequently buried deeper in the guidelines. But persons with disabilities are not a homogenous at-risk group, and intersecting vulnerabilities need to be documented and evaluated.<sup>183</sup> Considerations for how certain characteristics—such as age and sex—exacerbate vulnerabilities or increase resilience are critical. Disability should be both a variable to disaggregate data on and a variable that requires further disaggregation itself. To ensure a more intersectional approach, guidelines on sex, age, and disability should be integrated across and throughout programs, plans, and resources and not be a stand-alone document.

Depending on the context, social stigma, and family and community support, persons with disabilities have different capacities to meet their own needs. Thus, intersectional data and analysis are always needed to tease this nuance out. Preconceived notions of vulnerability and assumptions not

grounded in evidence can lead to overlooking capacities, poorly targeting programs, or completely missing the most vulnerable. Thus, disability-disaggregated data applied with an intersectional lens needs to inform evidence-driven responses at all stages in the humanitarian programming cycle, including diagnosis (risk and needs assessment), prescription, observation (baseline and monitoring), and prognosis (registration and evaluation).

Information on disability is frequently captured in clinics, but not in larger-scale surveys such as SMART. The Washington Group and UNICEF have jointly developed a Module on Child Functioning<sup>184</sup> that covers children 2 to 17 years of age and assesses functional difficulties in different domains, including hearing, vision, communication/comprehension, learning, mobility, and emotions. This or similar instruments should be used in contexts where disability is prevalent, such as natural disaster and conflict contexts, given that malnutrition and recovery from malnutrition are significantly worse in these populations. We recommend the shorter set of Washington Group disability questions should be utilized for adult nutrition surveys.





## CHAPTER 4 Conclusion and Recommendations

The principle of impartiality requires that humanitarian aid be provided solely on the basis of need. Disaggregating and analyzing data by sex, age, disability, diverse SOGIESC, and other relevant intersectional social categories allows for evidence-based design, implementation, targeting, monitoring, and assessment of humanitarian programs. Due to a lack of clear understanding of who is most at need and organizational capacity, current assumptions of vulnerability do not always hold up to the reality of what is happening to diverse and marginalized people experiencing crisis. A better understanding of how, when, where, and why to collect and analyze disaggregated data is required to help humanitarian actors accurately inform programs to address the scale and need of the most affected populations.

Published in 2011, *Sex and Age Matter* was a groundbreaking report that helped to influence the collection and use of sex-disaggregated data to inform humanitarian practice. Over the past decade, the humanitarian community has made some progress towards standardizing and sharpening the use of sex-disaggregated data and gender analysis to inform programming. However, the perception around how much progress has been made towards the collection and use of sex-disaggregated data and gender analysis does not match the reality of how much more needs to be done to make sure that the data collection is systematically collected, and that the data actually translate into humanitarian needs overviews and humanitarian response plans and overall programming.

While there is much to applaud in what has been achieved over the past decade in terms of the standardization of data collection tools and guidelines around sex-disaggregated data collection and gender analysis, the humanitarian community still has a long way to go. The collection and use of age-disaggregated data lags even farther behind, usually only regularly applied in nutritional or educational programming with children, or the recent emphasis on adolescents. With the noted exception of a few outstanding groups, almost no humanitarian donors or organizations prioritize older people in disasters, and they remain extremely underserved. Some humanitarian agencies are beginning to ramp up their collection and use of disability-disaggregated data, which is addition to the consistent collection of disability information. It is time for humanitarian donors and organizations to better understand when and how to prioritize diverse SOGIESC in data collection and programming, while ensuring to maintain the “do no harm” principle. Those with diverse SOGIESC are among the most neglected and poorly served by international humanitarian organizations. Recognizing, understanding, and addressing the experiences, needs, and priorities of diverse SOGIESC during crises is an area in which tremendous efforts are needed given the paucity of what is now occurring. We conclude that while some real strides have been made to move forward over the last decade, current data collection, analysis, and use are insufficient to accurately inform programming to identify and determine needs and priorities among a crisis-affected community.

Diverse sex, age, disability, and other intersectional identities of people experiencing crisis far exceed the current capacity of humanitarian agencies. For too long, the approach to address this increased need is through tasking them to already overburdened gender or child specialists. While gender, youth, and disability specialists continue to be essential, overall, the humanitarian sector needs to hire and train more robust, diverse, and inclusive teams to manage data collection, analysis, and program design for a variety of intersectional identities and social categories. For instance, today, most of the humanitarian agencies and programs we reviewed are not systematically collecting gender and age data, analyzing it, and using it to inform programing. In addition, the agencies and program do not take into account the needs of persons experiencing disabilities, older persons, or those with diverse SOGIESC in their programing in any meaningful way. As a result, we are looking at a humanitarian industry sworn to impartially aid people that is essentially missing at least 50% or more of the population in any given crisis context. Donors and organizations need to prioritize experts with skills in gender, youth, disability, older persons, data management, and data inclusivity to make sure they have the appropriate leads and knowhow to address the needs of these populations. Importantly, the creation of robust accountability mechanisms must serve as the foundation upon which these principles, guidelines and actions stand.

The entire humanitarian-development-peacebuilding career pipeline, including academia, needs to prioritize delivering the skills needed by employees and leadership to realize and carry out robust and inclusive assistance. These specific skills are wide ranging, from inclusive research design and methods, data management to expertise in gender, disabilities, diverse SOGIESC, children, youth, and older people.

The majority of our interview respondents indicated that one of the primary roadblocks for additional data collection and analysis was a lack of capacity and time and *in the field*, as starkly illustrated by the finding that in 2020, less than 20 percent of Humanitarian Country Teams had senior gender capacity for at least half of the year.<sup>185</sup> Collection and analysis support needs to be provided in the form of additional funding, expertise, *clear and concise* guidelines, and training on the appropriate tools, and robust accountability mechanisms. Without these underpinnings, any demand for increased data collection, disaggregation, and analysis is

going to overburden and overtax field staff who are already overworked and understaffed. Significant learning can be applied from the progress made around sex and gender despite the remaining gaps, with the existence of extensive training around the RGA, gender experts in headquarters and missions, the provision of simple and effective tools and guidelines, as well as the prioritization, funding, and mandates to collect and analyze sex-disaggregated data and to use gender analysis by donors. And yet there remains significant gaps in the use of SADDD in Humanitarian Needs Overviews and Humanitarian Response Plans.

Donor requirements can powerfully influence the collection and use of data to support evidence-based humanitarian response. Our research found that where donors mandated the collection of disability data while simultaneously providing appropriate funding, support, guidance, and expertise, disability data collection and analysis were prioritized and effectively used to inform programing. Donors are increasingly requiring, or at least recommending, SADDD. To be effective, requirements need to go hand in hand with appropriate funding and support and clear and rigorous accountability mechanisms. We found the greatest success in the collection and use of data when the push came from a combined effort of donors, academics, advocacy groups, and international bodies.

Finally, translating data to programs or program amendments is inconsistent and led to many interviewees questioning whether the data that are collected are sufficiently used to justify requests for more data collection. Given the amount of data collected in the humanitarian sector, greater investment is needed to manage and use that data, requiring investment in data management and data inclusivity experts. There needs to be more collaboration across data collection in the same contexts and efforts to make data publicly available (for example via data dashboards) for sharing with other experts, students, local organizations, and governments. Furthermore, funding for documentation of how the programs used the data is necessary to make sure that there is consistent and sharable learning across programs, sectors, and organizations, as well as accountability to the affected and surveyed population.

To continue to make progress on inclusive, effective, and impartial humanitarian aid, we offer the following recommendations.



## Recommendations for humanitarian donors and actors

- Using the Gender Accountability Framework and the IASC Gender Policy, create and enforce clear mechanisms to hold humanitarian actors accountable for the use of sex-disaggregated data and gender analysis to directly inform humanitarian needs overviews, response plans, program implementation and MEL.
- Continue to require that humanitarian agencies *gather and make use of* the input of women and girls affected by humanitarian crisis, and collect, analyze, *and make use of* sex disaggregated data to inform their humanitarian programming. Informed by this analysis, document the changes and adjustments made to programming and their impacts for lessons learned.
- Provide and mandate humanitarian actors to work with representative organizations and affected populations related to women, girls, persons experiencing disabilities, youth, older persons, and individuals with diverse SOGIESC to identify key challenges and barriers to inclusive programming and data collection, especially when internal expertise is not available. Where possible, work directly with local organizations, particularly in relation to persons experiencing disabilities and diverse SOGIESC where this can be done while “doing no harm”.
- Develop and mainstream standards for data disaggregation, management, and use for sex, age, disability, youth, older persons, and, when appropriate and safe, diverse SOGIESC populations.
- Make women, disability, youth, including adolescent girls, older persons, and diverse SOGIESC populations, when appropriate and safe, inclusion actions clear across all program documentation, including design, analysis, contracts, grant agreements, evaluation frameworks, and program reviews and evaluations.
- Mandate that sex, age, disability, and diverse SOGIESC, when appropriate and safe, data collection be part of the monitoring and evaluation process throughout.
- Working with key stakeholders, develop, provide, and pilot simple guidelines for data collection and analysis, including intersectional analysis around sex, age, disability, and diverse SOGIESC, taking into account learning from progress around gender and tools such as the RGA and the Diverse SOGIESC Rapid Assessment Tool.
- Mandate the disaggregation of relevant program-level data by sex, age, disability, and continuous age across both quantitative and qualitative data collection. Include requirements for intersectional analysis, with disaggregation within and across sex, age, and disability as a minimum.
- Mandate the use (and adaptation) of the Washington Group short set of questions on disability within data collection, ensuring sex and age are also collected and analyzed using gender analysis.
- Ensure adequate funding corresponds with the additional data collection, consultation, capacity building of field staff, data management, analysis, evaluation, and documentation needs that correspond to more inclusive programming.
- Invest in the hiring, training, and retaining inclusion specialists and/or data equity, gender, disability, diverse SOGIESC, and older persons specialists across departments. Some of these specializations can be combined in staff. In addition, ensure training for all relevant staff on these populations throughout the agencies.
- Invest in and provide continuous funding for upkeep of publicly available dashboards and data management staff for both anonymized quantitative and qualitative data collection, allowing for secondary data analysis, improved learning, and reduction of the burden of additional primary data collection. Provide guidelines for harmonized terminology, variable definitions, and quality standards for standard variables such as, sex, age, and disability. Examples of standards are: age needs to be collected and entered as a continuous variable; and disability needs to be collected using the Washington Group Questions.

- Provide support to ensure that 1) data findings are brought back to affected people and local partners, and 2) that data collected is analyzed and used for accountability purposes.

- Invest in documenting and making publicly available the impact of more inclusive data collection and programming on policy and program adaptation and key indicators to ensure learning across the humanitarian field.



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