

CHILDREN WITH DISABILITIES IN SITUATIONS OF ARMED CONFLICT

Discussion Paper

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Cover photo: © UNICEF/UN055883/AI-Issa Description: Saja, 13, plays with her football. She lost her left leg to a bomb attack in Syria.

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INTRODUCTION

During armed conflict, children with disabilities are caught in a vicious cycle of violence, social polarization, deteriorating services and deepening poverty. Global estimates suggest there are between 93 million and 150 million children with disabilities under the age of 15.1 Given that disability is often not reported due to stigma there is reason to believe actual prevalence could be much higher. Although efforts to ensure the fulfilment of their rights have improved, girls and boys with disabilities continue to remain among the most marginalized and excluded segment of the population. This is amplified during situations of armed conflict. The barriers to full participation they face on a day-to-day basis are intensified and compounded when infrastructure is destroyed, and services and systems are compromised and made inaccessible. This results in the further exclusion and marginalization of children with disabilities, and prevents them from accessing schooling, health and psychosocial support, or a means of escape from conflict.

When systems and services break down, children are also left more susceptible to violence. A review of studies shows that children with disabilities are more likely than other children to experience violence, including sexual violence,² and that this vulnerability is heightened in humanitarian crises.³ The practice of institutionalization of children with disabilities also increases their exposure to violence⁴ and further complicates the task of protecting civilians.5 History provides several examples such as the NaziT-4 programme of extermination of adults and children with disabilities, and the slaughter of civilians with disabilities at a psychiatric hospital during the Rwandan genocide. In fact, the existence of clustered settlements, such as psychiatric hospitals, orphanages, social care homes and other institutions has led to the use of people with disabilities as human targets or shields by some combatants.

Injuries sustained by many children during armed conflict may also lead to long-term impairments. There are six grave violations of children's rights and protection in armed conflict that are on the agenda of the United Nations (UN) Security Council; killing and maiming, recruitment and use of children, rape or other sexual violence, abduction, attacks on schools or hospitals, and denial of humanitarian access. The grave violations can result in physical and psychological injuries that can lead to long-term impairments. Two key treaties - the Convention on the Rights of Persons with Disabilities (CRPD) and the Convention on the Rights of the Child (CRC) and its Optional Protocol on the involvement of children in armed conflict - protect the rights of children with disabilities. Although the rights and principles set forth in these Conventions apply in situations of armed conflict, they are all too often eroded by the violence, stress, hunger, social breakdown and poverty that armed conflict brings.

Governments around the world have committed themselves to respect, promote, and fulfil the rights of children with disabilities, including in situations of armed conflict, and progress is being made. Efforts by a broad range of actors to implement the CRPD, CRC and other human rights instruments include the development of standards to address the rights and needs of persons with disabilities in humanitarian crises, and guidance on making humanitarian response, development and peacebuilding more inclusive. Efforts to improve the collection and use of data concerning children and adults with disabilities are also underway.

Yet, as this discussion paper makes clear, much more needs to be done. Investments in disability-inclusive humanitarian action and recovery from crises will pay off, contributing towards a dividend of peace built on greater equality, tolerance and justice.



A teacher helps Grade 2 student DuuaaTounnes, who is blind, assemble a wooden puzzle during a class in Al Walidia Basic School in the north-eastern Homs Municipality, near the Syria-Lebanon border.

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FROM THE MEDICAL TO THE Social and human rights-Based Approach to disability

FRAMING THE UNDERSTANDING OF DISABILITY

Several models and theories have been proposed to explain disability. An out-dated but still prevalent approach views disability as a set of medical problems requiring correction or rehabilitation. This medical model defines children and adults with disabilities by their impairments. Its aim is to "normalize" children and adults with disabilities so that they fit into society.

Beginning in the 1970s, with the strengthening of the disability rights movement, a new approach evolved: the social model. Those in the movement argue that the medical approach to defining disability is oppressive. Instead, they draw a distinction between impairment and disability, viewing disability as a socially created construct rather than a set of attributes of individuals. This social model of disability focuses on the barriers created by the environment such as lack of physical access to buildings, transportation and information. The barriers also encompass the attitudes and prejudices of society, the policies and practices of governments, and the often-exclusionary structures of health, welfare, education and other systems.

The CRPD has further developed the social model by recognizing that individuals' impairments must be considered and addressed through a human rights-based approach. The human rights-based approach to disability moves from the treatment of persons with disabilities as objects of charity, medical treatment and social protection, towards viewing persons with disabilities as people with rights who are capable of claiming those rights and making decisions that affect their lives, as well as being active members of society.⁶

THE NORMATIVE FRAMEWORK

The international normative framework related to children with disabilities in armed conflict is primarily based on human rights law and international humanitarian law. As noted above, the CRPD, ratified by 177 States as of November 2018, recognizes that individuals' impairments must be considered and addressed through a human rights-based approach. Disability is described as an "evolving concept" that "results from the interaction between persons with impairments and attitudinal and environmental barriers that hinder their full and effective participation in society on an equal basis with others."⁷ The CRPD "establishes a powerful framework for challenging the social exclusion and discrimination faced by children with disabilities."⁸

The CRPD sets out general principles to promote and protect the rights of children and adults with disabilities. The principles reflect many years of advocacy by persons with disabilities and Organizations of Persons with Disabilities (or DPOs, as they are commonly known) against discrimination, disrespect, exclusion and poverty:

- Respect for inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons;
- Non-discrimination;
- Full and effective participation and inclusion in society;
- Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity;
- Equality of opportunity;
- Accessibility;
- Equality between men and women;
- Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities.⁹



These and related principles are found in several other conventions, declarations and action plans for improving the lives of children. For example, they reflect the principles underpinning the CRC and the Convention on the Elimination of All Forms of Discrimination against Women (CEDAW). The CRPD's principles of non-discrimination, equity and social inclusion — as well as investing in children and promoting well-being for all at every age — are also bulwarks of the 2030 Agenda for Sustainable Development and the Sustainable Development Goals.

These principles are fundamental to a respectful society open to all, and governments have the primary responsibility to uphold them, including during times of conflict and occupation, and regardless of legal status or nationality. Both the CRC and CRPD call for measures of protection of children, and of adults and children with disabilities, respectively, in situations of armed conflict.¹⁰

While both human rights law and international humanitarian law apply in situations of armed conflict, there exists tension between the two bodies of law in how they view disability. International humanitarian law tends to rely on older medical definitions of disability that emphasize impairment and vulnerability, reflecting a paternalistic approach based on the medical model described above.¹¹ International humanitarian law views persons with disabilities primarily in terms of their impairments. One example is the way Geneva Convention III describes unquestionable cases given the right to direct repatriation: cases of amputation, total blindness or deafness and mental disorder.¹² This is because many instruments of international humanitarian law, like the Geneva Conventions of 1949, were adopted when medical models of disability were predominant.¹³

The primarily medical approach of international humanitarian law can lead to unwanted consequences when a purely treatment-focused lens is adopted. For example, many people with long-term impairments, such as children and adults who are deaf or who have psychosocial or intellectual disabilities, may not be medically vulnerable or require treatment, but they still face barriers in accessing services, information and communication.

The CRPD and other instruments of human rights law are helping to influence international humanitarian law

to incorporate a greater human rights perspective. The CRPD, in Article 11, calls for international humanitarian law to be viewed through the human rights-based approach to disability.¹⁴ One example of the influence of human rights law is the 2008 Convention on Cluster Munitions, which recognizes the rights and dignity of victims of cluster munitions, as well as the risks of discrimination that they face. In doing so, it addresses the social dimensions of disability.¹⁵

The UN Security Council has started to address disability through its protection frameworks. In a 2013 resolution on women, peace and security, the Security Council called for multi-sectoral services for survivors of sexual violence that are inclusive of women with disabilities and eliminate barriers to accessing services.¹⁶ In 2015, the Security Council highlighted concerns about children and adults with disabilities – including risks of abandonment, violence, lack of access to basic services and exclusion. In the same year, it required the UN mission in the Central African Republic to report on abuses against children and adults with disabilities in that country.¹⁷ The Security Council has also addressed the need to support the reintegration of mine victims with disabilities, and to ensure the

protection of persons with disabilities from violence.¹⁸ In a 2018 resolution, it called for addressing the needs of all children, including children with disabilities in areas such as access to health care, psychosocial support and education programmes.¹⁹

As noted above, the CRPD applies to all persons with disabilities regardless of legal status or nationality. This means that countries must align their policies on refugees with the principles of the Convention. In 2010, the Executive Committee of the Office of the United Nations High Commissioner for Refugees (UNHCR) emphasized the need for States to provide sustainable and appropriate support for "refugees and other persons with disabilities", recognizing the need to align policies on refugees with the CRPD. The Executive Committee called for accessible communications for refugees and for paying special attention to refugees who have difficulty communicating their own needs, as well as for participation of refugees and other persons with disabilities in the design of programmes. It furthermore called on States, UNHCR and partners to enable children and youth with disabilities to access appropriate protection, assistance and education.²⁰



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IMPACT OF ARMED CONFLICT ON Children with disabilities

DETERIORATION OF INFRASTRUCTURE AND REDUCED ACCESS TO SERVICES

During armed conflict, the lives of children with disabilities are affected by deteriorating services, increasing need and deepening poverty. Poverty and service breakdown may even contribute to starting this cycle. Indeed, some of the most protracted armed conflicts of recent decades began with government disinvestment in health, education and other social services, often in the name of economic reform. In countries like Sierra Leone, Sudan and the Syrian Arab Republic, this disinvestment was one of several factors that polarized societies and pushed them towards conflict.²¹ Further, research indicates that violations of human rights, including economic and social rights, increase the risk of civil war.²²

Children with disabilities are especially affected when health care and other social service infrastructure deteriorates. To begin with, these children, and their families and caregivers, are more likely than others to be poor and excluded.²³ As mentioned above, armed conflict further erodes the rights of children with disabilities and their access to services in many ways.²⁴ It often compromises health care and rehabilitation services²⁵ as well as centres providing social support. Families may have to pay out of their own pockets for services that were formerly free.²⁶ In times of conflict, inflation may decrease the value of financial assistance accessed by people with disabilities. Rising costs combined with deteriorating security and transport services further reduce access to services. Even when governments try to provide universal access to services, the provision of these services is often fragmented.

The destruction of infrastructure can create physical barriers that reduce access to other systems, such as education. For example, attacks on schools can reverse progress on inclusion, pushing previously included children with disabilities into domestic isolation or exploitative work, such as begging. Because of these and related factors, poverty intensifies for everyone, and households with persons with disabilities have a deeper, longer experience of poverty.²⁷

A 2018 survey of Syrian refugees living in Jordan and Lebanon starkly illustrated the effect of armed conflict on persons with disabilities. It found that families looking after a member with an impairment, injury or disability faced more unfavourable economic conditions than families in the wider refugee population. These families had fewer opportunities for employment, lower income levels, and higher debt.²⁸ This disparity was more evident when their access to services, such as health care, was compared: households with persons with disabilities were less likely than other households to have access to required medical services.²⁹

Children with disabilities also face barriers to accessing education in emergency settings. The 2018 study of Syrian refugees in Jordan and Lebanon noted above found that among children 13 years of age and above, refugees with disabilities were more likely to be illiterate and to have never been enrolled in school. Among children 6-12 years of age, children with disabilities were more likely to have never been enrolled or to have dropped out of school. A 2013 study in Iraq found that only 16 per cent of displaced children with disabilities living in camps and 10 per cent living in urban areas were attending schools around Domiz, Northern Iraq. Prior to displacement, 29 per cent of children with disabilities living in camps and 27 per cent living in urban areas were attending school.³⁰ According to a 2018 report by Syria Relief, four out of five children living with disabilities inside the Syrian Arab Republic reported not having access to education.³¹

Children with disabilities face increased isolation and discrimination in situations of armed conflict.³² Sometimes, mobility difficulties or the loss of assistive devices make it difficult for children to escape from danger. In panicked flight, children and adults with disabilities may get left behind. In several recent conflicts, families or caregivers who were overwhelmed by the violence, stress or costs of war abandoned children and adults with disabilities.³³ Conflict and displacement may also undermine solidarity



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and empathy, and disrupt the support networks that allow children to cope with disabilities.

Often, children with disabilities acquire new, secondary conditions during conflict and displacement.³⁴ The impacts of these situations can be significant. For example, if children with spinal cord injuries do not receive quality care, they develop an increased risk of secondary conditions such as pressure sores and urinary tract infections.³⁵ A 2014 study on the Syrian crisis showed that refugees with disabilities have an increased risk of acquiring new conditions due to untreated chronic diseases.³⁶

During conflict and displacement, health facilities may find it harder to mitigate the impact of complications in childbirth. As a result, infants may experience prenatal complications due to the physical stress experienced by their mothers. Maternal starvation and malnutrition can also lead to permanent fetal damage and miscarriage. Babies subjected to malnourishment during fetal development are at a higher risk of neonatal diseases, and later in life may have chronic health conditions, such as diabetes or metabolic, endocrine and cardiovascular diseases.³⁷ Children with HIV are also affected by a lack of access or breakdown of services during armed conflict: many stop adhering to treatment.³⁸

When immunization coverage shrinks, children can acquire long-term impairments as a result.³⁹ For example, efforts to eradicate infectious diseases such as poliomyelitis are often hampered.⁴⁰ This occurred in the Syrian Arab Republic, where siege of civilian areas has been used as a tactic since the beginning of the armed conflict. A breakdown of services and a lack of humanitarian access to certain parts of the country were linked to polio outbreaks in that country in 2013.⁴¹

Depression is a common secondary condition that is aggravated during conflict and displacement. For example, half of the respondents to the 2014 survey of Syrian refugees in Jordan and Lebanon reported frequent or permanent signs of psychological distress.⁴²

The effects of an armed conflict on persons with disabilities can continue long after the conflict ends. Recent studies of twentieth-century wars show how armed conflict can result in psychological impairments that can cross generations. Some people who survived the World War II Nazi terror as children experienced post-traumatic stress disorder five decades later, and studies suggest that their children and grandchildren are also affected.⁴³ Violence against pregnant women can have long-term effects on children, including premature birth and low birthweight.⁴⁴

The use of indiscriminate weapons can also result in disability long after the conflict: people exposed to mustard gas in the Islamic Republic of Iran in the 1980s, or to depleted uranium from the 1990s onwards, report problems in reproductive health. Their children have a higher risk of a range of congenital disorders that may lead to disability.⁴⁵ Children living today in areas of Viet Nam contaminated by the herbicide Agent Orange in the 1970s are more likely to have neurological damage and other health problems that are implicated in many physical and developmental impairments. Their families report exacerbated poverty, inadequate access to education, health and disability services, bullying and stigmatization.⁴⁶

There are examples of how to mitigate the effects of armed conflict on services and infrastructure. One of them is the experience of Nepal. During 10 years of conflict from 1996 to 2006, the country made progress on nearly every health indicator of the Millennium Development Goals. There are several possible explanations. First, parties to the conflict did not attack health infrastructure, allowing the Government and former rebels to keep health posts staffed in areas under rebel control. Second, the public health system focused provision of services towards disadvantaged groups, including children and adults with disabilities. Third, with UN and donor support, access to health facilities increased substantially during the conflict, and local groups managing health facilities ensured effective representation from various disadvantaged sectors of the community.47

CHILDREN WITH DISABILITIES AND THE SIX GRAVE VIOLATIONS AGAINST CHILDREN

The UN Security Council has identified six grave violations affecting children in situations of armed conflict. These include (1) killing and maiming, (2) recruitment and use of children, (3) rape or other sexual violence, (4) abduction, (5) attacks on schools or hospitals, and (6) denial of humanitarian access.⁴⁸ Children with disabilities are impacted by all six grave violations. The results may be that children acquire disabilities for the first time, experience the exacerbation of existing disabilities, or develop secondary

disabilities. In addition to being violations of international law, these and other violations against children, left unaddressed, undermine the possibility of resolving conflict and have life-altering implications for children.

To document these violations, the Security Council established the Monitoring and Reporting Mechanism (MRM) on grave violations against children in situations of armed conflict.⁴⁹ As of November 2018, Country Task Forces for Monitoring and Reporting (CTFMRs) are active in 20 situations of armed conflict where they are tasked with documenting the impact of armed conflict on children.⁵⁰ In addition to documenting the grave violations against children, CTFMRs engage with armed forces and armed groups listed in the annexes of the Secretary-General's annual report on children and armed conflict. The purpose of this engagement is to secure commitments from perpetrators to end and prevent violations against children through the development of time-bound action plans. These action plans may be one entry point to ensure that the rights and needs of children with disabilities are addressed.

In 2017 alone, CTFMRs verified more than 21,000 violations against children.⁵¹ While violations documented through the MRM shed light on the number of children who are seriously injured, the MRM does not document the number of children who acquire disabilities during armed conflict. One exception was the specific information included in the Secretary-General's 2015 report on children and armed conflict. The report indicated that about 3,000 of over 9,000 injuries verified by UN monitors occurred in the State of Palestine, and about 1,000 of those injuries were likely to lead to disabilities.⁵²

Of the grave violations on the agenda of the Security Council, maiming is the one most clearly associated with the creation of new or secondary disabilities. In the context of the MRM, the term maiming refers to "any action that causes a serious, permanent, disabling injury, scarring or mutilation to a child".⁵³ Although the Security Council uses the term broadly to capture all violations against children that result in serious injury, "maiming" should not be used to describe someone's disability, given the stigmatizing nature of the term.

Historically, maiming has been used in conflict in many countries, including the Democratic Republic of the Congo, Kenya and Viet Nam. Twentieth-century colonial armies used amputation and other forms of visible, symbolic injuries to spread terror among populations they sought to control. In post-colonial wars, such as in Sierra Leone, these tactics were reprised, and often children were

Verified cases of child maimings documented by the UN Monitoring and Reporting Mechanism on grave violations against children in situations of armed conflict⁶⁷

Situation of concern	Cases documented in 2016	Cases documented in 2017
Afghanistan	2,589	2,318
Central African Republic	32	43
Colombia	2	35
Democratic Republic of the Congo	116	178
Iraq	181	438
Israel and State of Palestine	930	1,172
Lebanon	864	12
Libya	68	38
Mali	35	15
Myanmar	13	47 ⁶⁵
Nigeria	184	311
Philippines	24	17
Somalia ⁶⁶	1,121	931
South Sudan	71	57
Sudan	124	81
Syrian Arab Republic	647	361
Thailand	27	0
Yemen	838	764

targeted.⁵⁴ In these situations, armed opposition groups used the deliberate, visible "disablement" of children and adults to demonstrate the powerlessness of government, to polarize local societies, and to grab international attention.⁵⁵ Records from one Monrovia hospital operating during the second Liberian civil war suggest that about 10 per cent of war-related amputations in 2003 were performed on children.⁵⁶

Maiming also includes those injuries resulting from landmines and other explosive remnants of war (ERW), such as cluster munitions. In some cases, children are disproportionately at risk of injuries from weapons that are used indiscriminately. In 2016, there were at least 1,544 child casualties from these weapons, the highest annual total since the Landmine and Cluster Munition Monitor began recording them in 1999. This represents more than 40 per cent of all civilians killed or injured from these weapons.⁵⁷ Anti-personnel mines are more likely to cause damage in smaller bodies, with most of the injuries leading to long-term impairments or death. In rural areas, child herders and farmers often encounter landmines and ERW, and children are more likely than adults to mistake explosive remnants for toys.

The other grave violations may also result in long-term impairments. Children may be impaired from physical or psychological injuries brought about by sexual violence. These injuries include traumatic fistulas, which cause incontinence, distress and social stigma for women and girls. Most fistulas can be successfully treated by surgery but sometimes their social and psychological aftermath can lead to long-term psychological conditions and stigma.⁵⁸ Children who are recruited or used by armed forces or armed groups are exposed to combat injuries and may be particularly vulnerable to injuries from landmines and ERW. In some cases, children are used to explore known minefields. In Cambodia, a survey of mine victims in military hospitals found that 43 per cent had been recruited as soldiers when they were between the ages of 10 and 16.⁵⁹ Some studies have shown that child soldiers have high rates of post-traumatic stress reactions.⁶⁰ Research has consistently shown post-traumatic stress disorder to be associated with impairments in functioning across a number of psychosocial areas.⁶¹

Other violations that can lead to long-term impairments include the denial of humanitarian access and attacks on infrastructure such as schools and health centres. Denial of humanitarian access can result in chronic health conditions, such as malnutrition or poliomyelitis, that can lead to or exacerbate long-term impairments. It is often a deliberate tactic of armed conflict.

Attacks on health centres accelerate the breakdown of health systems that might otherwise mitigate the impact of injury or illness and prevent long-term or secondary impairments from occurring. Children and adults with disabilities are further excluded by assaults on health centres and schools if the destruction of infrastructure renders facilities inaccessible.

A 2012 study, based on interviews of 713 survivors of injuries in Colombia, Haiti, Pakistan and Uganda, sheds light on the impact of war-related injuries. The persons interviewed were 15-35 years of age at the time of their injuries, and predominantly less educated, and from marginalized and poor communities. Most sustained longterm impairments, which undermined their livelihoods, limited their educational opportunity and left them even more marginalized. Most received immediate health care, but few had access to long-term rehabilitation and health care because treatment was expensive or inaccessible.⁶²

In situations of armed conflict, many children with disabilities are harder to identify than other children and are less visible, especially to policymakers and serviceproviders. This holds true for children whose disabilities arise from sexual, psychological or other wartime traumas. And it holds even more true for children whose experience of disability began before the armed conflict, or whose disabilities are not directly caused by conflict but rather are aggravated by it.

Armed conflict can lead decision-makers, who often must act quickly, to prioritize impairments by political importance and expediency. This affects the way that adults and children with disabilities are represented in political debate and what services they receive. In many instances, societies tend to favour the experiences of war-wounded people. This may occur because of the perceived sacrifices these individuals have made for a specific cause or military objective. This often means that the experiences of children with pre-existing disabilities that are less visible, such as intellectual disabilities and post-traumatic stress, are of a lesser priority. Children with these less visible disabilities or injuries that are not associated with a specific cause often face reduced access to already scarce services and resources, and remain underrepresented in decision-making. 63

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STRENGTHENING HUMANITARIAN ACTION

DISABILITY-INCLUSIVE Humanitarian Action

Children and adults with disabilities are often overlooked in access to humanitarian assistance. This can be attributed to lack of awareness, inaccessibility, stigma and discrimination, or to lack of capacity of humanitarian personnel, among other factors. For example, stigma and discrimination can lead humanitarian workers to exclude children with disabilities (particularly those with visible disabilities) in the belief that the preservation of the life of a child with a disability is of lower priority than that of a child who does not have a disability.⁶⁸

To strengthen the inclusion and participation of children and adults with disabilities, most humanitarian actors agree on the need for a twin-track approach to humanitarian response. This response should encompass interventions that are inclusive of persons with disabilities as well as those that are targeted towards persons with disabilities. In other words, humanitarian actors should design and adapt mainstream humanitarian programmes and interventions to ensure they are inclusive of and accessible to all children, including children with disabilities, and, in parallel, develop interventions to directly address the needs of children with disabilities.

However, the commitment to a twin-track approach to humanitarian action has not always translated into practice. For example, a 2015 review of the humanitarian system found limited progress on mainstreaming disability.⁶⁹ For another study in 2015, 30 children and 370 adults with disabilities directly affected by humanitarian crises were interviewed. Most of them reported that they did not have information on or access to the basic services they said they needed, such as health, food or shelter. The situation was worse in humanitarian crises caused by armed conflict.⁷⁰

A review of humanitarian funding, undertaken in 2012, revealed the near invisibility of people with disabilities in humanitarian response. The study looked at all 6,003 projects submitted to the UN Consolidated Appeals Process and Flash Appeals in 2010 and 2011. Less than two per cent of projects included at least one activity targeting people with disabilities, and only around one-third of these were funded. Over the two-year period, the appeals received \$10.9 billion in contributions. Projects with at least one activity targeting people with disabilities were allocated \$62.9 million, which is only about 0.5 per cent of total funding.⁷¹

Several significant efforts are under way to make humanitarian assistance for children and adults with disabilities more inclusive. In 2016, participants to the World Humanitarian Summit adopted a <u>Charter on Inclusion</u> of Persons with Disabilities in Humanitarian Action.⁷²

The Charter recognizes the urgent need for humanitarian action that includes children and adults with disabilities, acknowledging the disproportionate risks and the multiple, intersecting forms of discrimination they face. Among other measures, the Charter's signatories commit themselves to eliminate discrimination in humanitarian policy, to promote the participation of persons with disabilities and of their representative organizations, and to develop inclusive policies and inclusive services.⁷³

Following the World Humanitarian Summit and the launch of the Charter, the Inter-Agency Standing Committee⁷⁴ formed a task team to develop guidelines on inclusion of persons with disabilities in humanitarian action. The guidelines, due to be launched in mid-2019, will aim to assist humanitarian actors, governments and affected communities to coordinate, plan, implement, monitor and evaluate essential actions that foster the effectiveness and efficiency of humanitarian action. The goal is to have the full and effective participation and inclusion of persons with disabilities, along with improved practice across all sectors and throughout humanitarian action.

In 2017, UNICEF released <u>guidance on including children</u> <u>with disabilities in humanitarian action</u>⁷⁵ as a series of booklets providing concrete recommendations for the development of disability-inclusive programming in the areas of education, child protection, health/HIV, nutrition, and water, sanitation and hygiene. There is also guidance on disability-inclusive shelter and settlements in emergencies that provide practical measures on how to enhance accessibility of physical spaces in humanitarian situations."⁷⁶

Additional efforts to make humanitarian response more disability-inclusive include the current revision of the <u>Sphere Standards and the Child Protection Minimum</u> <u>Standards</u>⁷⁷, and the <u>Humanitarian Inclusion Standards</u> for older people and people with disabilities.⁷⁸ The latter calls for a modest additional allocation of resources of about four per cent. This would allow for critical service-provision, such as accessible latrines, appropriate assistive technologies and transport. The standards also identify an important, often overlooked means for promoting disability-inclusive humanitarian action: hiring staff and volunteers with disabilities in front-line humanitarian posts.

RELIABLE DATA

Policymakers need data to respond adequately to the social, economic, political and cultural barriers that impact the lives of children and adults with disabilities. Similarly, policymakers need data to ensure that the rights and needs of children with disabilities are addressed during humanitarian crises. However, there are several challenges to collecting data on disability. These challenges make it difficult to compare statistics across, but also within, countries, and render much of the available data unreliable.

First, armed conflict seriously undermines the process of collecting quantitative evidence of any kind. Methodological factors, particularly approaches to sampling, exert considerable influence over findings about prevalence of disability. Further, there is a lack of general agreement among a large number of stakeholders on definitions of disability that can be operationalized for data collection. Variations in definition may reflect differences in culture and language, and they may also reflect various aims of data collection. Medical models of disability have exercised a considerable influence on data collection and have often relied on stigmatizing labels and definitions that vield low prevalence estimates. Restrictive, impairmentbased definitions are often used when disability data are linked to welfare entitlements. Some disabilities are difficult to detect in early childhood, and young children are sometimes excluded from data collection exercises entirely.

Finally, the methods and systems for collecting data on disability need improvement. To begin with, the personnel

collecting data do not always have adequate capacity, tools or systems to reliably capture disability. Even when programmatic data on access to humanitarian assistance and services are collected, they are not disaggregated by disability status. Therefore, this data does not provide necessary information on service needs, utilization and gaps for persons with disabilities. Registration data for refugees is similarly inadequate, as the population of children and adults with disabilities is not always accurately reflected. For example, a 2014 survey of Syrian refugees in Jordan and Lebanon found that 22 per cent had a disability. In contrast, only 1.4 per cent of UNHCR-registered refugees in Lebanon were recorded as having a disability.⁷⁹

Reporting injuries through surveys likewise needs improvement. Currently, human rights and child protection personnel working in situations of armed conflict follow passive surveillance approaches, responding with investigations only to injuries that are reported. They need to use population-based surveys that can identify both reported and non-reported injuries. Such surveys give a more accurate sense of scale as well as a better understanding of entry points for action.

UNICEF and other UN agencies are working to improve the precision and comparability of statistics on the prevalence and incidence of disability. Statisticians and other stakeholders have identified a recommended methodology for the disaggregation of Sustainable Development Goals data for adults and children.⁸⁰ The recommended approach was developed by the Washington Group on Disability Statistics (WG), which established the <u>WG Short Set of Questions⁸¹ and, in collaboration with UNICEF, the WG/UNICEF Child Functioning Module.⁸²</u>

This framework allows the collection of reliable data on children and adults with disabilities that are comparable cross-nationally. Since its adoption in 2006, the WG Short Set of Questions has been used in several countries considered to be contexts of high humanitarian risk. Responses to the Short Set of Questions are yielding prevalence data on persons with disabilities and allowing the disaggregation of other data by disability status. While efforts are ongoing to validate the use of the WG Short Set of Questions and the WG/UNICEF Child Functioning Module in humanitarian crises, there is general agreement among a wide range of stakeholders that the WG tools should be used in data collection efforts at the national level, including in censuses and surveys. Such data can provide valuable baseline information in the event of a crisis and facilitate identification of needs and follow-up.

MEANINGFUL PARTICIPATION

It is crucial to support the participation of children with disabilities in humanitarian planning and decision-making for humanitarian response, and further in recovery and peacebuilding. Meaningful participation helps to improve understanding of the rights and needs of children with disabilities, which is essential to humanitarian response. Governments need to take the lead in finding mechanisms for their participation, working closely with Organizations of Persons with Disabilities (DPOs) and other stakeholders. Humanitarian actors need to consult with children and adults with disabilities in determining the best approaches.

The African Union has developed approaches to using peace and security architecture to support people with disabilities. The organization proposes more inclusive emergency planning and peacebuilding, and protection for the dignity of persons with disabilities in forced displacement. The African Union strategy has a welcome focus on the structured participation in peacebuilding and protection of persons with disabilities, both as individuals and as members of Organizations of Persons with Disabilities.⁸³ UNICEF has also produced <u>guidelines on how</u> to effectively consult children with disabilities.⁸⁴

Experiences reinforce the value of participation of persons with disabilities. Leading up to the World Humanitarian Summit a stakeholder analysis was conducted in the Middle East and North Africa which included interviewing refugees and other people receiving aid across the region. Respondents rated aid agencies on a 10-point scale. Their low ratings indicated that respondents were largely dissatisfied with the way they were treated by humanitarian workers in several domains: treating people with respect and dignity, being neutral and impartial, making people feel safe and protected from violence, meeting priority needs, helping people prepare for future crises, and considering the opinions of those receiving aid.⁸⁵

One of the key lessons of working with children with disabilities is that there is no shortcut to ensuring their representation. It requires redoubled and often long-term efforts, considering the myriad of barriers and risks faced by these children, including multiple forms of stigma and discrimination. Children with disabilities need diverse mechanisms for participation as well as appropriate accommodation and support. Organizations of Persons with Disabilities (DPOs) should be involved in these efforts.

INVESTMENT IN PEACE

The disability rights movement advocates for the construction of a more inclusive society that respects the dignity, autonomy and differences of children and adults with disabilities, on an equal basis with all children and adults. The disruptions and political flux brought about by conflict can provide a starting point for this kind of change once conflict ends.

Children and adults with disabilities have a key role to play in resolving conflict and in post-conflict reconstruction. Therefore, the international peace and security architecture needs to accommodate the participation of children and adults with disabilities and of Organizations of Persons with Disabilities. Children with disabilities can play a significant role in mechanisms such as transitional justice to address the legacies of past human rights violations. Over the past few decades, several truth and reconciliation commissions in Africa, Asia, and Latin America have issued reports on children with disabilities.⁸⁶

Governments, parties to armed conflict, and other national and international actors must prioritize the inclusion of children and adults with disabilities in planning and decision-making in the response to armed conflict, and later in peacebuilding. Protecting the safety and rights of children with disabilities yields positive results for other children and adults, too. It benefits society as a whole. In that sense, it is an investment in sustainable peace.



A girl from Atfaluna ("Our Children") Society for Deaf Children, a local NGO in Gaza, State of Palestine. The organization offers education and vocational training, as well as free health care and psychosocial services.

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RECOMMENDATIONS

- Harmonize national laws and policies with international instruments protecting the rights of children with disabilities. Member States who have not done so should ratify the CRPD, the Optional Protocol to the CRC on the involvement of children in armed conflict and other relevant instruments, as appropriate.
- 2. Involve children with disabilities. Humanitarian personnel, peacekeepers and other humanitarian actors must ensure that girls and boys with disabilities and their families participate throughout humanitarian response – from planning to implementation, data collection, monitoring and evaluation, and in recovery and peacebuilding. Provide appropriate support and accommodation such as sign language interpretation and transport assistance.
- 3. Enhance the capacities and knowledge of personnel in peace operations on the rights and needs of persons with disabilities in humanitarian contexts. Add specific modules to existing pre-deployment and special training materials on child protection for all personnel in peace operations, including civilian, military and police, to enable them to understand the perspectives, needs and strengths of children with disabilities in situations of crisis.
- 4. Enhance the capacities and knowledge of development and humanitarian personnel on the rights and needs of persons with disabilities in humanitarian contexts. Develop guidance for development and humanitarian personnel to enable them to understand the perspectives, needs and strengths of children with disabilities in situations of crisis.
- 5. Understand the needs and experiences of children with disabilities in humanitarian action. Ensure that humanitarian needs assessments, response plans, and reporting identify needs and barriers faced by children with disabilities. Document violations against the rights of children with disabilities, including discrimination and denial of humanitarian assistance.

- 6. Improve the collection and use of data. Build the capacity of humanitarian and other personnel collecting data. Ensure that data are disaggregated by disability, age and sex. Make greater use of population-based surveys to capture reported and non-reported injuries. Improve information and registration systems for conflict-affected populations, including refugees. Incorporate the Washington Group Short Set of Questions and the Child Functioning Module into surveys, censuses and other data collection efforts. Develop and report on disability-specific indicators to support monitoring of inclusion and accessibility of humanitarian programmes and services.
- 7. Adopt a twin-track approach. Promote inclusion and accessibility for children with disabilities in humanitarian programmes and services, including preparedness measures, evacuation procedures, and early warning systems. Regular programmes and services for children such as education, protection, health and nutrition, and water sanitation and hygiene should take into account accessibility standards and inclusion. Ensure the availability of targeted programmes to cover needs of children with disabilities such as rehabilitation and provision of assistive devices.
- 8. Conduct accessibility assessments to improve understanding on whether children with disabilities are able to benefit from humanitarian relief and use emergency shelters, toilets, washing facilities, and health, education and other services. Take steps to eliminate identified barriers.
- 9. Assess and respond to the heightened risks of violence, exploitation and abuse faced by children with disabilities. Strengthen the capacity of case management systems to include children with disabilities by addressing capacity gaps among caseworkers and barriers to information and communication in the provision of services. Ensure that mechanisms to prevent and respond to gender-based violence, as well as sexual and reproductive health

services are designed to be accessible to children with disabilities, particularly girls.

- 10. Reflect violations against children with disabilities and incidents of injuries to children resulting in disability in the documentation of grave violations of child rights through the Monitoring and Reporting Mechanism. Action plans to prevent and respond to grave violations against children should address the needs of conflictaffected children with disabilities.
- 11. Review rules of engagement and standard operating procedures on protection of civilians to ensure they adequately cover children. Member States should proactively review the rules of engagement and standard operating procedures of their security forces on protection of civilians to ensure they provide sufficient protection for children, including children with disabilities, and are established prior to the onset of conflict. These efforts can be supported by UN agencies through Security Sector Reform and other technical support processes.



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