

# GUIDANCE NOTE Qualitative Assessment Approaches for the Protection of Children with Disabilities Within Humanitarian Contexts



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## I. Executive Summary<sup>1</sup>

Children with disabilities are particularly vulnerable in humanitarian settings, yet they are often not able to access the services and protection they need. While multiple factors create these barriers, a major cause is how data about children with disabilities is collected and mapped. Data collection processes often exclude or underrepresent the views of children with disabilities and their caretakers. When the experiences of children with disabilities and their caretakers are not defined and collected, they become excluded from mainstreamed protective services, which are meant to serve all children. Children with disabilities also do not get the specialised interventions they need.

This guidance note explores how to use qualitative methods to create more robust assessment processes to ensure more effective programming and services for children with disabilities.<sup>2</sup> This note provides promising practices for engaging with children with disabilities and includes sample tools that can be tailored to fit the needs of a particular assessment process. The note also explores the importance of thoughtful cross-sectoral responses so that children with disabilities, and their families, are carefully considered in areas like water, sanitation, and hygiene (WASH), education, health, and nutrition, and therefore receive the holistic support they need and deserve.

This note is intended for a broad audience of relevant child protection actors, including practitioners, coordination groups, researchers, and donors. The information is not limited to one type of humanitarian setting, geographic region, or culture. As a result, the practices and guidance should be adapted to each specific context, ideally in partnership with well-informed local actors, such as representatives from local organisations for persons with disabilities.

#### Key findings from the note include:

- Many data collection tools deployed within humanitarian scenarios utilise overly simplistic and/or incomplete definitions of disability. Only by first identifying the Who in discussions of persons with disabilities can effective assessments take place.
- When appropriately tailored to the context, assessment and data collection processes can identify key information about children with disabilities and their families, including measuring how many children with disabilities are in a given area, mapping existing services and gaps; mapping existing capacities, especially organisations of persons with disabilities (OPDs); and providing an understanding of the ways in which the crisis may be affecting children with disabilities and their access to cross-sector services (e.g., education, health, food).
- Qualitative research can help surface the perspectives, needs, and priorities of children with disabilities and their caretakers and provide an understanding of how they define the risks, barriers, and protective factors. The direct voices of children with disabilities and their caretakers are critical. Qualitative approaches can help ensure that the experiences of children with disabilities are prioritised, and that protective and risk factors and needs as they see them are represented within the analysis that will guide the creation of effective interventions.

<sup>1</sup> This note was researched and written by Emily Kaplan and Stephen Hanmer D'Elía. Critical inputs and feedback were provided by key individuals and organisations, including Alliance for Child Protection in Humanitarian Action member organisations, UNICEF, Handicap International, Save the Children Alliance, Terre des Hommes, and UNICEF Office of Research–Innocenti.

<sup>2</sup> This note is embedded within a broader initiative of the Alliance for Children Protection in Humanitarian Action focused on Prevention.

- To effectively lead qualitative research, the first step is to assemble the team, which should include trained assessors. When selecting assessors, it is important to consider context. Having facilitators who are of a similar demographic to the participants (gender, ethnicity, those who identify as a person with a disability) can create comfort for the participants to open up. There are also some universal qualities/skills that assessment team members should possess, including: fluency in the language of the participants; a non-judgemental and respectful demeanour; empathy and good listening skills as well as skills in accessible communication.
- Key ethical principles to bear in mind throughout assessment processes include the concept of "do no harm" and safeguarding children from further harm; informed consent as well as confidentiality; accountability; and meaningful participation. <sup>3</sup>
- Before deciding on the exact qualitative approach(es), it is critical to consult with people who have direct experience with the target population and the context at hand. Key informant interviews and/or focus group discussions can provide foundational information to guide the qualitative processes and tailor the approach to the area and humanitarian situation.



3 The Alliance for Child Protection in Humanitarian Action, A Reflective Field Guide: Community-level Approaches to Child Protection in Humanitarian Action, 2020).

## **II. KEY TERMS**

**Risk factors** are the threats and vulnerabilities leading to an increased likelihood of harmful outcomes, including physical, emotional, or psychological danger, harm, or distress, while **protective factors** support well-being.<sup>4</sup> Both risk and protective factors can be found across multiple levels: individual, family, community, and society.<sup>5</sup>

**OPDs:** Organisations of persons with disabilities (OPDs) are non-governmental organisations led, directed, and governed by persons with disabilities, who should compose a clear majority of their membership. They are sometimes known as representative organisations or disabled peoples' organisations (DPOs).<sup>6</sup>

"**Universal design**," or good design that benefits everyone, was first coined by architect Ron Mace in the 1980s.<sup>7</sup> The Convention on the Rights of Persons with Disabilities defines it as "the design of products, environments, programmes and services to be usable by all people, to the greatest possible extent, without needing adaptation or specialized design."<sup>8</sup> As summarised by UNICEF in its *Toolkit on Accessibility*, the seven principles that underpin universal design are:<sup>9</sup>

- 1. Equitable use providing the same means of use for all users, with and without disabilities.
- 2. Flexible in use accommodating individual preferences and abilities, such as left- or right-handedness.
- 3. Simple and intuitive use ensuring easy to understand utilisation, including for people with low literacy.
- 4. Perceivable information communicating key information clearly and in multiple ways.
- 5. Error tolerance minimising hazards and adverse consequences of accidental actions.
- 6. Low physical effort requiring little operating force to use.
- 7. Size and space providing appropriate space for reach and use, if seating or standing.

Accessibility Continuum: UNICEF's Toolkit on Accessibility outlines the concept of the accessibility continuum and four aspects to consider to ensure it: reaching a facility; entering a facility; moving around a facility; and using specific features of a facility.<sup>10</sup> Failure to consider the full continuum might lead to barriers in accessibility—for example, a response team dedicated to WASH in a village affected by a humanitarian scenario may design a community latrine that is fit for use by children with disabilities; however, if there is no way for children in wheelchairs to reach the latrine, it remains inaccessible, despite being designed as "inclusive" of children with disabilities.

<sup>4</sup> The Alliance for Child Protection in Humanitarian Action, Primary Prevention Framework for Child Protection in Humanitarian Action (The Alliance for Child Protection in Humanitarian Action, 2021).

<sup>5</sup> The Alliance for Child Protection in Humanitarian Action, Primary Prevention Framework for Child Protection in Humanitarian Action (The Alliance for Child Protection in Humanitarian Action, 2021).

<sup>6</sup> United Nations Children's Fund, <u>'Engaging with organizations of persons with disabilities in humanitarian action,'</u> Disability Inclusive Humanitarian Toolkit (UNICEF).

<sup>7</sup> United Nations Children's Fund, Toolkit on Accessibility (UNICEF, 2022).

<sup>8</sup> United Nations, Convention on the Rights of Persons with Disabilities (New York: UN, 2006).

<sup>9</sup> United Nations Children's Fund, Toolkit on Accessibility (UNICEF, 2022).

<sup>10</sup> United Nations Children's Fund, Toolkit on Accessibility (UNICEF, 2022).

## **III. BACKGROUND**

#### a) Who Are Children with Disabilities?

Many data collection tools deployed within humanitarian scenarios utilise overly simplistic and/or incomplete definitions of disability.<sup>11</sup> Only by first identifying the Who in discussions of persons with disabilities can effective assessments take place.

According to the Convention on the Rights of Persons with Disabilities, **"persons with disabilities include those who have long-term physical, mental, intellectual, or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others."<sup>12</sup> Broad categories of disability include: communication disorders; learning disabilities; sensory disabilities; developmental disabilities; mental health disorders; intellectual disabilities; and physical disabilities.<sup>13</sup>** 

It is equally important to maintain an awareness of the significant diversity within the population of children with disabilities. An **intersectionality** of factors (age, gender, ethnicity, race, impairment type, level and type of support needs) make children with disabilities an incredibly heterogeneous group. Within the larger category of "children with disabilities," there are subcategories of children who may need increased protection and who may be more vulnerable than others. Similarly, children living in households that include someone with a disability should also be considered.

It is also important to consider disability and the affected population within a context. **Contextual** factors may include:

- Awareness of and attitudes towards disability, including any stigma, in a certain place and the policies/frameworks that protect children with disabilities.
- Extent to which pre-existing services in a location are inclusive of and accessible to children with disabilities.
- Presence of OPDs—as well as their experience level and resources—in a particular place.<sup>14</sup>

Finally, different models of disability can impact the context, particularly regarding attitudinal barriers. For example, in societies that rely on the medical model, disability is often viewed as an illness that people "suffer from and should be cured."<sup>15</sup> However, in societies that embrace a human rights-based model, persons with disabilities are entitled to the same rights and opportunities as persons without disabilities, and governments, as well as society as a whole, are responsible for protecting those rights.<sup>16</sup>

<sup>11</sup> United Nations Children's Fund, Humanity & Inclusion, and the International Disability Alliance, Including Everyone: Strengthening the Collection and Use of Data About Persons with Disabilities in Humanitarian Situations (New York: UNICEF, 2019).

<sup>12</sup> United Nations, Convention on the Rights of Persons with Disabilities (New York: UN, 2006).

<sup>13</sup> Inter-agency Network for Education in Emergencies, "Supporting Young Children with Disabilities in Humanitarian Settings" (webinar), June 28, 2022.

<sup>14</sup> IASC Task Team on Inclusion of Persons With Disabilities in Humanitarian Action, *Inclusion of Persons With Disabilities in Humanitarian Action* (IASC, 2019).

<sup>15</sup> Inter-agency Network for Education in Emergencies, "Supporting Young Children with Disabilities in Humanitarian Settings" (webinar), June 28, 2022.

<sup>16</sup> Inter-agency Network for Education in Emergencies, "Supporting Young Children with Disabilities in Humanitarian Settings" (webinar), June 28, 2022.

#### b) How Many Children with Disabilities Are There?

Persons with disabilities make up approximately 15% of the world's population,<sup>17</sup> and this number is increasing. The World Health Organization has estimated that this population will double by 2050.<sup>18</sup> More specifically, 1 in 10 children has a disability.<sup>19</sup> A recent UNICEF report projected there are about 240 million children with disabilities throughout the world.<sup>20</sup> However, these estimates are likely low. Stigma and cultural contexts that influence how different populations define and view disability often leads to underreporting.<sup>21</sup> This is especially true in humanitarian contexts.<sup>22</sup>

Within humanitarian contexts, approximately 7 million children with disabilities are impacted annually, a number that is also likely an underestimate.<sup>23</sup> The 2022 Global Humanitarian Overview published by OCHA estimates that there are approximately 274 million people requiring humanitarian assistance, which would mean approximately 41 million people (including children) with a disability.<sup>24</sup>

#### c) What Protection Challenges Impact Children with Disabilities?<sup>25</sup>

Children with disabilities are:

- Less likely to have their births registered (additionally, in contrast to children without disabilities, the likelihood that they will be registered does not increase as they age).
- More likely to experience disruptions in education.<sup>26</sup>
- More likely to experience increased economic hardship for their families,<sup>27</sup> including fewer job opportunities, lower income, and higher debt.<sup>28</sup>
- More than twice as likely as their peers without disabilities to experience violence.
- A third more likely than children without disabilities to experience severe physical punishment at home.
- At a higher risk of experiencing online sexual abuse and exploitation, including involvement in child sexual abuse material.
- At greater risk of violence, exploitation, abuse, and neglect when they live in residential care institutions.
- At risk of social isolation, violence, abuse, and death due to superstition and cultural practices (in some cultural contexts).

23 Mabel Giraldo, "Children With and Without Disabilities in Disasters: A Narrative Overview of Play-based Interventions into the Humanitarian Programmes and Researches," in *Perspectives and Research on Play for Children With Disabilities*, ed. Daniela Bulgarelli (Warsaw: De Gruyter Sciendo, 2020), 61–82.

- 25 Where not otherwise footnoted, the information presented in this section is adapted/excerpted from United Nations Children's Fund, 'Unicef Fact Sheet: Children with Disabilities,' New York, 2022, <u>https://www.unicef.org/media/128976/file/UNICEF%20Fact%20</u> <u>Sheet%20:%20Children%20with%20Disabilities.pdf</u> pp. 41-44.
- 26 Human Rights Watch, "UN: High Risk in Conflicts for Children With Disabilities," <u>https://www.hrw.org/news/2022/02/02/un-high-risk-conflicts-children-disabilities</u>, February 2, 2022.
- 27 American Academy for Cerebral Palsy and Developmental Medicine, "Children with Disabilities in Armed Conflicts: A Call for Humanitarian Actions for Children," <u>https://www.aacpdm.org/events</u>, accessed July 20, 2022.
- 28 United Nations Children's Fund, Children With Disabilities in Situations of Armed Conflict (UNICEF, 2018).

<sup>17</sup> Humanity & Inclusion (formerly Handicap International), Disability in Humanitarian Contexts: Views From Affected People and Field Organisations (Lyon: Humanity & Inclusion, 2015).

<sup>18</sup> Anilkrishna B. Thota et al., Effectiveness of Inclusive Interventions for Children with Disabilities in Low- and Middle-Income Countries (Florence: UNICEF Office of Research – Innocenti, 2022).

<sup>19</sup> IASC Task Team on Inclusion of Persons with Disabilities in Humanitarian Action, *Inclusion of Persons With Disabilities in Humanitarian Action* (IASC, 2019).

<sup>20</sup> United Nations Children's Fund, "Nearly 240 Million Children With Disabilities Around the World, UNICEF's Most Comprehensive Statistical Analysis Finds," https://www.unicef.org/press-releases/nearly-240-million-children-disabilities-around-world-unicefs-mostcomprehensive, November 9, 2021.

<sup>21</sup> United Nations Children's Fund, Children with Disabilities in Situations of Armed Conflict (UNICEF, 2018).

<sup>22</sup> Humanitarian Coalition, "What is a Humanitarian Emergency?" www.humanitariancoalition.ca/what-is-a-humanitarian-emergency, accessed July 20, 2022.

<sup>24</sup> See https://gho.unocha.org/ Accessed November 26, 2022.

Additionally:

- Adolescents with disabilities are disproportionately vulnerable to physical and sexual violence, and to child or forced marriage. They are also routinely denied access to justice or redress.
- Girls with disabilities are up to three times more at risk of rape than girls without disabilities and are twice as likely to experience other forms of gender-based violence (GBV), as well as often suffering more severe injuries and more prolonged abuse after having experienced GBV.

The stigma and prejudice that remain common towards children with disabilities often result in parents and families hiding their children and denying them access to other children and the broader community, including schools and health care facilities. In these cases, violence and abuse might be more difficult to identify and report.

Children with disabilities often face attitudinal barriers due to **ableism**—the underlying system of values that results in stigma, discrimination, and, ultimately, the exclusion of persons with disabilities from development and humanitarian action. Due to ableist assumptions, children with disabilities are considered to be in need of "fixing," to be less able to contribute and participate, to be less worthy of attention and are considered to have less inherent value than other children.<sup>29</sup>



<sup>29</sup> Excerpted from United Nations Children's Fund, 'UNICEF Fact Sheet: Children with Disabilities,' New York, 2022, p.5. Despite increased barriers and challenges faced by children with disabilities in humanitarian contexts, these scenarios can, in some ways, offer critical opportunities for change. Organisations that are providing services and protection in humanitarian contexts are often forced to rethink their standard modes of operation which can lead to more open-minded and inclusive approaches. This can create a "silver lining" to the "cloud" of the humanitarian crisis—an opportunity to include and improve the lives of those who may have previously been overlooked.

## **IV. QUALITATIVE ASSESSMENT APPROACHES**

#### a) The Importance of Qualitative Data Collection

Children with disabilities are often excluded from child protection efforts because they are overlooked and not meaningfully engaged by the assessments and data collection processes that inform child protection strategies.<sup>30</sup> In order to overcome these barriers, a robust framework for understanding inclusion and accessibility is needed when assessing needs and collecting data in humanitarian contexts.

Qualitative data can add vital insight. In particular, it helps shed light on the personal perspectives of children with disabilities, their families, and the organisations that already exist to support them and/or represent them (i.e., OPDs). Qualitative approaches can help ensure that their voices are prioritised and that protective and risk factors and needs as they see them are represented within the analysis that will guide the creation of effective interventions.

Qualitative methods are a critical part of gathering and analysing comprehensive data regarding risk and protective factors for children with disabilities in humanitarian settings. Qualitative approaches—including participatory methods, like direct interviews as well as direct observation—can allow children and adults with disabilities, as well as their families, to have their perspectives heard, ensuring the most relevant information *as deemed by them* is included within the assessment process. These methods can be extended to include additional key stakeholders, such as local organisations and professionals who work with children with disabilities (e.g., speech therapists and occupational therapists) to add their insights, which can add critical contextual information to an assessment. It is important to note that these organisations and individuals should not take the place of hearing directly from persons with disabilities themselves.

### Humanitarian Specific Challenges to Qualitative Research

Humanitarian settings create unique challenges for doing qualitative research. Outside actors do not have the time necessary to form deep, trusting bonds with community members that lead to meaningful communication, especially in the acute stages of a humanitarian situation.<sup>31</sup> This lack of trust may amplify taboos so that participants who are hesitant to speak about some subjects may be even less likely to bring those subjects up. Aware of the vulnerabilities of those with disabilities, community members may also be reluctant to identify themselves and their children to outsiders. This may create major gaps in the research findings or understanding of the context. And finally, security constraints and/or physical barriers may limit the ability of assessment team members and participants to come together.<sup>32</sup>

<sup>30</sup> United Nations Children's Fund, Including Children with Disabilities in Humanitarian Action: General Guidance (UNICEF, 2017).

<sup>31</sup> The Alliance for Child Protection in Humanitarian Action, A Reflective Field Guide: Community-level Approaches to Child Protection in Humanitarian Action, 2020).

<sup>32</sup> The Alliance for Child Protection in Humanitarian Action, A Reflective Field Guide: Community-level Approaches to Child Protection in Humanitarian Action (The Alliance for Child Protection in Humanitarian

#### b) Ensure the Right Assessment Team

To effectively lead qualitative research, the first step is to assemble the team, which should include trained assessors.<sup>33</sup> When selecting assessors, it is important to consider context. Having facilitators who are of a similar demographic to the participants (gender, ethnicity, those who identify as a person with a disability) can create comfort for the participants to open up.<sup>34</sup> There are also some universal qualities/skills that assessment team members should possess, including: fluency in the language of the participants; a non-judgemental and respectful demeanour; empathy and good listening skills as well as skills in accessible communication;<sup>35</sup> and previous experience and training conducting qualitative research and/or needs assessments. Even with prior professional experiences, training is critical to align all team members on the selected approach, tools, and situation prior to conducting any qualitative data collection, and additional trainings can be offered throughout the process, if needed.<sup>36</sup>

#### c) Create a Welcoming & Safe Environment

Although there are challenges to doing qualitative research in humanitarian settings, a number of ethical considerations and best practices can help ensure inclusion, as well as safety and respect, for all participants. Key ethical principles to bear in mind throughout assessment processes include the concept of "do no harm" and safeguarding children from further harm; informed consent as well as confidentiality; accountability; and meaningful participation.<sup>37</sup>

To create a welcoming environment for meaningful participation, one that respects the rights, strengths, and dignity of children and adults with disabilities, all participating staff should be appropriately trained, including on respectful communication with persons with disabilities.<sup>38</sup> This training may include skills like child- and disability-friendly interviewing<sup>39</sup> (for an overview of effective communication practices, see Practical Communication Tips text box).

Assessment team members can take steps such as asking participants with disabilities what communication modes and formats are preferable/appropriate (including alternatives to oral or written communication like pictures<sup>40</sup>). When engaging children directly via interviews or focus groups, creative methods, including introductory games, can also create a level of comfort for them.<sup>41</sup>

In addition, a **welcoming physical environment** is important. Accessibility and reasonable accommodation should be considered when choosing the location of assessment activities,<sup>42</sup> configuring the room, and providing transportation (or covering of transportation costs). The concept of **universal design** (and its seven underlying principles) and the **accessibility continuum** can provide helpful guidance (for more detail on both, see Key Terms).

- 33 The Global Protection Cluster, Child Protection Rapid Assessment Toolkit (The Global Protection Cluster, 2012).
- 34 The Global Protection Cluster, Protection Mainstreaming Toolkit (The Global Protection Cluster, 2017).
- 35 The Global Protection Cluster, Protection Mainstreaming Toolkit (The Global Protection Cluster, 2017).

- 39 The Alliance for Child Protection in Humanitarian Action, Minimum Standards for Child Protection in Humanitarian Action, 2019 Edition (The Alliance for Child Protection in Humanitarian Action, 2019).
- 40 The Alliance for Child Protection in Humanitarian Action, *Minimum Standards for Child Protection in Humanitarian Action*, 2019 Edition (The Alliance for Child Protection in Humanitarian Action, 2019).
- 41 The Alliance for Child Protection in Humanitarian Action, *Identifying and Ranking Risk and Protective Factors: A Brief Guide* (The Alliance for Child Protection in Humanitarian Action, 2021).

<sup>36</sup> World Vision International, Evaluation of Child Friendly Spaces: Tools and Guidance for Monitoring and Evaluating CFS (World Vision International, 2015).

<sup>37</sup> The Alliance for Child Protection in Humanitarian Action, A Reflective Field Guide: Community-level Approaches to Child Protection in Humanitarian Action, 2020).

<sup>38</sup> European Civil Protection and Humanitarian Aid Operations, *The Inclusion of Persons with Disabilities in EU-funded Humanitarian Aid Operations* (European Commission, 2019).

<sup>42</sup> European Civil Protection and Humanitarian Aid Operations, *The Inclusion of Persons with Disabilities in EU-funded Humanitarian Aid Operations* (European Commission, 2019).

The safety of participants is also important, and assessors should be thoughtful and cautious when exploring qualitative topics. Avoid including questions that could, within the specific context, cultural, or humanitarian setting, put participants at risk. Pay attention to non-verbal cues that could signal that participants feel uncomfortable discussing a specific topic in front of others.<sup>43</sup> And ensure the anonymity of participant responses to further protect their security.<sup>44</sup>

#### d) Consult with Key Individuals & Organisations

Before deciding on the exact qualitative approach(es), consult with people who have direct experience with the target population and the context at hand. Key informant interviews and/or focus group discussions can provide foundational information to guide the qualitative processes and tailor the approach to the area and humanitarian situation. Participants could include the families and caregivers of children with disabilities, relevant community leaders (including, as applicable, religious leaders, teachers, etc.), and other stakeholders, such as members/leaders from local OPDs, child protection officers, and government officials. <sup>45</sup>

## Practical Communication Tips<sup>46</sup>

Below are a range of practical communication tips, both for when interacting directly with children with disabilities and their families/caregivers (such as during interviews with children and their parents), as well as when creating qualitative assessment materials. In addition, these communication best practices can be applied when creating messaging on behalf of children with disabilities, such as for advocacy purposes.

#### Use thoughtful terminology intended to empower children with disabilities:

- Use "person-first terminology" to acknowledge the child's full identity ("child with a disability," rather than a "disabled child").
- Avoid wording that views disability as a negative, or something that is "suffered from" (such as "wheelchair user," rather than "confined to a wheelchair").
- Do not use "normal or regular" ("normal people") as terms in opposition to persons with disabilities—instead opt simply for "persons without disabilities."

#### Support children with disabilities in their communication:

- Display patience and confirm that you have received what the child is expressing.
- As is helpful/necessary, employ professionals who can further support the child's communicative process (such as sign language interpreters, speech therapists, etc.). These professionals can also support and provide guidance for caregivers to better understand their children.
- If a child has trouble understanding or communicating, use objects as is helpful (to indicate), pictures and/or drawings.

<sup>43</sup> The Global Protection Cluster, Protection Mainstreaming Toolkit (The Global Protection Cluster, 2017).

<sup>44</sup> The Global Protection Cluster, Protection Mainstreaming Toolkit (The Global Protection Cluster, 2017).

<sup>45</sup> The Alliance for Child Protection in Humanitarian Action, *Identifying and Ranking Risk and Protective Factors: A Brief Guide* (The Alliance for Child Protection in Humanitarian Action, 2021).

<sup>46</sup> Adapted and Excerpted from United Nations Children's Fund, Including Children with Disabilities in Humanitarian Action: General Guidance (UNICEF, 2017).

#### Consider accessibility when adapting information:

- Produce materials that contain information—especially vital humanitarian information in a range of formats, to ensure children with a diversity of disabilities (and their families) can easily understand content. Formats might include large print, Braille, and audio versions (for persons with visual disabilities); visual imagery (for persons with intellectual disabilities); text messages and captioning (for persons with hearing disabilities).
- Consider engaging partners—from local OPDs, for example—to review materials with regard to accessibility before disseminating widely.

#### Depict children with disabilities in an empowering and inclusive way:

- Use communications as an opportunity to combat negative or limiting stereotypes towards children and adults with disabilities.
- Include images of persons with disabilities in all materials, not just those specifically meant for or related to persons with disabilities, to adequately depict diversity.
- In these images, integrate children and persons with disabilities in groups of those without disabilities, rather than depicting them as separated, and depict them engaging in a range of activities.
- Adapt existing materials and communication tools to further raise awareness about and be inclusive of disability. Suggestions for such adaptations that could be integrated into the Minimum Standards for Child Protection in Humanitarian Action, for example, are included in Appendix B.
- Directly involve children with disabilities in communication and engagement campaigns, empowering them as major participants in the creation of messaging and depictions of persons with disabilities.



#### e) Focus on Participation47

Meaningful participation can be challenging to achieve in an authentic and inclusive way. However, it is critical. Participation must be ensured for the most vulnerable and potentially marginalised, including, within the broader umbrella of children with disabilities, specific groups that may be at higher risk (depending on context, this might include indigenous children with disabilities, girls with disabilities, children with disabilities who are refugees, etc.).

Participation should include not only children with disabilities themselves, but also their families (including representatives from households with children that include a person with a disability outside of the child), relevant OPDs, and community-based organisations.<sup>48</sup> Engaging all of these stakeholders allows for those most affected to have their views included within the assessment process. These groups can offer critical first-hand knowledge to help shape an understanding of contextual and cultural factors that may impact protection, access, and inclusion for children with disabilities. This sort of collaborative work with local individuals and entities can take significant trust and relationship-building, which requires concerted effort as well as time.

#### f) Select Appropriate Qualitative Data Collection Tool(s)

Once the qualitative process has been refined using the insights of key individuals and organisations, another key preparatory step will be the selection of an appropriate data collection tool or tools, which will vary based on the qualitative methods selected. Regardless of the tool selected (and adapted), consistency is critical. The same tool(s) should be used for observations and notes and the same analysis methods should be used<sup>49</sup> throughout the entire process. When refining questions to be asked via interviews, a questionnaire, or other qualitative approaches, the language used, and in particular language within context, is extremely important. Avoid outdated terms (such as "handicapped child," instead use "child with a disability") (see Practical Communication Tips text box for examples of appropriate language). Also keep in mind that the language preferred by persons with disabilities and affirming wording might vary depending on the context.<sup>50</sup> Furthermore, it might vary based on the preferences of each individual, as children with disabilities are a highly heterogeneous group. Having key informants, including representatives from local OPDs, review data collection tools and assessment questions before use can help ensure that the team is using language that is acceptable and appropriate for the target population.

<sup>47</sup> For additional guidance on participations see Save the Children, <u>The Nine Basic Requirements for Meaningful and Ethical Children's</u> <u>Participation</u>, 2021.

<sup>48</sup> European Civil Protection and Humanitarian Aid Operations, *The Inclusion of Persons With Disabilities in EU-funded Humanitarian Aid Operations* (European Commission, 2019).

<sup>49</sup> The Global Protection Cluster, Protection Mainstreaming Toolkit (The Global Protection Cluster, 2017).

<sup>50</sup> Zero Abuse Project, Interviewing Children with Disabilities: A Practical Guide for Forensic Interviewers (Zero Abuse Project, 2022).

#### 1. Interviewing Children with Disabilities

Direct conversations (interviews) with children with disabilities can be one of the most informative qualitative processes. They provide children the opportunity to describe their personal experiences, in their own words, which is an empowering process in and of itself. In addition, they can provide critical insights regarding their perspectives on key protective and risk factors, strengths and challenges, and an understanding of their humanitarian context.

Facilitating interviews require significant training and it often takes time to develop the trust and rapport necessary to allow a child to safely open up.<sup>51</sup> In addition, there is a power dynamic at play when conducting research with children. The researcher inherently holds more power than the child,<sup>52</sup> which is further exacerbated when that child is in a more vulnerable position due to disability and/or other marginalised identity. This dynamic must be carefully considered when designing and implementing qualitative methods.

One way to alleviate this power dynamic is to **interview children**, when possible, in their own homes and allow them to choose the particular location within the home to conduct the conversation.<sup>53</sup> This will allow the children to choose a space where they feel safe, while also allowing the assessor to observe them within their own environment. If a home-based interview is not possible, the assessor should remove barriers to participation and rapport-building and collaborate with participants to choose centrally-located, accessible locations, and/or cover transportation costs.<sup>54</sup> The physical layout of the space (and the items within it) should be considered with regard to universal accessibility and the comfort of the participating child.

Where possible and not onerous for the family, meeting with the child's primary caregiver(s) prior to the interview provides information that will help the assessor ensure the unique needs of each child are being considered. Caretakers can offer personalised insights as to what will make their child feel safe and more welcomed as well as contextual information to guide the assessor's interaction with that particular child.<sup>55</sup> When meeting with the caretakers, the assessor can ask a range of questions, including but not limited to:

- Physical and sensory considerations/needs;
- Use of assistive devices;
- Particular interests, forms of expression, etc.; and
- Cultural considerations.

Creating a sense of trust and ease with the child will lead to a deeper level of engagement and a richer set of findings. As a first step, the assessor should frame why they are meeting with the child and gain the child's permission to carry out an interview.<sup>56</sup> The assessor can also use this time to set "ground rules" that empower the child, for example they can demonstrate ways the child can share if they do not want to speak about a particular topic or engage in a particular activity and emphasise that doing so will have no consequences.<sup>57</sup>

<sup>51</sup> The Alliance for Child Protection in Humanitarian Action, A Reflective Field Guide: Community-level Approaches to Child Protection in Humanitarian Action, 2020).

<sup>52</sup> Gail Teachman and Barbara E. Gibson, "Children and Youth With Disabilities: Innovative Methods for Single Qualitative Interviews," *Qualitative Health Research* 23, no. 2 (2013), 10.1177/1049732312468063.

<sup>53</sup> Gail Teachman and Barbara E. Gibson, "Children and Youth with Disabilities: Innovative Methods for Single Qualitative Interviews," *Qualitative Health Research* 23, no. 2 (2013), 10.1177/1049732312468063.

<sup>54</sup> United Nations Children's Fund, Including Children with Disabilities in Humanitarian Action: General Guidance (UNICEF, 2017). For example, if the place of interview for a child in a wheelchair requires the child to be carried up a few flights of stairs (i.e. no elevator), it already puts the child in an uncomfortable position, rendering trust building harder.

<sup>55</sup> Gail Teachman and Barbara E. Gibson, "Children and Youth with Disabilities: Innovative Methods for Single Qualitative Interviews," *Qualitative Health Research* 23, no. 2 (2013), 10.1177/1049732312468063.

<sup>56</sup> The Global Protection Cluster, Protection Mainstreaming Toolkit (The Global Protection Cluster, 2017).

<sup>57</sup> Gail Teachman and Barbara E. Gibson, "Children and Youth with Disabilities: Innovative Methods for Single Qualitative Interviews," *Qualitative Health Research* 23, no. 2 (2013), 10.1177/1049732312468063.

The assessor can collect data using a flexible "toolkit" of methods to engage participants, rather than a single, set activity. This could include, though not be limited to, puppet play and role play scenarios.<sup>58</sup> In addition, the toolkit can include physical items to support effective communication such as: easel paper for drawing ideas that cannot be shared verbally, a stylus or pointer for indicating items or people physically present in the space, and assistive devices and/ or items like weighted blankets and fidget toys to help a child feel at ease.<sup>59</sup> Being prepared with a toolkit allows the assessor to tailor the engagement in a way that reflects each child's particular capacities (for example, a child who is visually-impaired may not be able to or be interested in participating in an activity like cartoon captioning). In addition, it allows the assessor to adapt the approach as the session continues and as they discover which methods make each child feel most comfortable and engaged.

Throughout the process, the assessor should be mindful not to ask questions that, within the specific context, cultural, or humanitarian setting, could put the child at risk, particularly if others are present within earshot. The assessor should remain alert to non-verbal cues from the child that could signal they feel uncomfortable about discussing a specific topic.<sup>60</sup> The assessor should be open to questions from participants as they come, maintaining a dialogue rather than interrogating the child.<sup>61</sup> Above all, the assessor should approach the child as a fellow human being, helping to alleviate some of the innate power dynamics at play and ensure the assessor is safeguarding the dignity and rights of the child throughout the process.<sup>62</sup> (See text box above on "Practical Communication Tips" for additional tips to support sensitive interviewing.)

#### 2. Direct Observation

Direct observation strategies provide information that can round out findings from interviews. Direct observation can be particularly useful to gain insights into issues that might be too sensitive or challenging to ask about in interviews.<sup>63</sup>

Direct observation can be combined with interviews—though assessors should be aware of the potential of observation bias—or done at sites that are most relevant depending on the identified protective and risk factors within the community and the context of its particular humanitarian scenario (e.g., distribution centres, camps, etc.).

For a sample data collection tool for direct observation—which can and should be adapted based on the assessors' specific needs and the assessment context/type of humanitarian setting please see pp. 57–60 of The Global Protection Cluster's Child Protection Rapid Assessment Toolkit. The toolkit also contains, as relevant, a key informant interview collection tool with sample questions (though it should be noted that the toolkit is not designed to support interviews with children themselves) and a site report template, alongside other resources.

<sup>58</sup> Gail Teachman and Barbara E. Gibson, "Children and Youth With Disabilities: Innovative Methods for Single Qualitative Interviews," Qualitative Health Research 23, no. 2 (2013), 10.1177/1049732312468063.

<sup>59</sup> Zero Abuse Project, Interviewing Children with Disabilities: A Practical Guide for Forensic Interviewers (Zero Abuse Project, 2022).

<sup>60</sup> The Global Protection Cluster, Protection Mainstreaming Toolkit (The Global Protection Cluster, 2017).

<sup>61</sup> The Global Protection Cluster, Protection Mainstreaming Toolkit (The Global Protection Cluster, 2017).

<sup>62</sup> Gail Teachman and Barbara E. Gibson, "Children and Youth With Disabilities: Innovative Methods for Single Qualitative Interviews," *Qualitative Health Research* 23, no. 2 (2013), 10.1177/1049732312468063.

<sup>63</sup> The Global Protection Cluster, Child Protection Rapid Assessment Toolkit (The Global Protection Cluster, 2012).

#### 3. Focus Groups<sup>64</sup>

Focus groups with relevant stakeholders can be an extremely useful means to identify and assess protective and risk factors. Groups can and should include children with disabilities themselves, their families and caregivers, relevant community leaders (which, depending on the context, could include religious leaders, teachers, etc.), and other stakeholders (staff of OPDs, other service providers, child protection officers, and government officials).<sup>65</sup> When identifying participants, the organisers should look to include individuals with a range of disabilities.<sup>66</sup> Each group should have its own discussion with 7–10 participants separated by age and role.<sup>67</sup>

The focus groups should ideally be run by two trained individuals: a facilitator, and a note-taker (who, as needed, doubles as a translator) who can allow the facilitator to focus solely on engaging the discussion participants without worrying about recording their responses.<sup>68</sup> The two-person facilitator team model helps ensure that, should any participant need to leave the room due to delicate/emotional subject matter, one facilitator can tend to the individual's needs while the other continues with the group.<sup>69</sup>

When scheduling focus groups, it is important to consider key logistics, including a centrallylocated setting that will be accessible for all (especially those with disabilities) and a time of day expressed as convenient by the majority of participants. Assessment team members can schedule key informant interviews with individuals who, for whatever reason, are not able to or do not feel comfortable participating in focus groups.

Once arranged, the focus groups can provide an ideal framework to identify, rank, and assess protective and risk factors. Participants can rank each factor in order of how much (or how little) it affects child protection in their eyes, and the facilitators can lead discussion surrounding responses as well as differing viewpoints.<sup>70</sup>

Beyond protective and risk factors, focus groups—as well as key informant interviews—can be effective settings to identify and assess barriers in place that might affect access, inclusion, and protection for children with disabilities. Key topics for questions to explore may include the presence (and enforcement) of standards regarding accessibility; barriers that existed prior to the crisis versus those that have emerged due to it; and attitudinal factors that may lead to discrimination and how these vary across types of disability.<sup>71</sup>

For a sample questionnaire to support the process of utilising focus groups to identify and rank protective and risk factors, as well as sample questions—both of which can and should be modified for the specific assessment process—and instructions, please see pp.17–26 The Alliance for Child Protection in Humanitarian Action's Identifying and Ranking Risk and Protective Factors: A Brief Guide

<sup>64</sup> Adapted from The Alliance for Child Protection in Humanitarian Action, *Identifying and Ranking Risk and Protective Factors:* A Brief Guide (The Alliance for Child Protection in Humanitarian Action, 2021).

<sup>65</sup> The Alliance for Child Protection in Humanitarian Action, *Identifying and Ranking Risk and Protective Factors: A Brief Guide* (The Alliance for Child Protection in Humanitarian Action, 2021).

<sup>66</sup> IASC Task Team on Inclusion of Persons With Disabilities in Humanitarian Action, *Inclusion of Persons With Disabilities in Humanitarian Action* (IASC, 2019).

<sup>67</sup> The Alliance for Child Protection in Humanitarian Action, *Identifying and Ranking Risk and Protective Factors: A Brief Guide* (The Alliance for Child Protection in Humanitarian Action, 2021).

<sup>68</sup> The Global Protection Cluster, Protection Mainstreaming Toolkit (The Global Protection Cluster, 2017).

<sup>69</sup> The Global Protection Cluster, Protection Mainstreaming Toolkit (The Global Protection Cluster, 2017).

<sup>70</sup> The Alliance for Child Protection in Humanitarian Action, *Identifying and Ranking Risk and Protective Factors: A Brief Guide* (The Alliance for Child Protection in Humanitarian Action, 2021).

<sup>71</sup> European Civil Protection and Humanitarian Aid Operations, *The Inclusion of Persons with Disabilities in EU-funded Humanitarian Aid Operations* (European Commission, 2019).



## **V. SELECT RESOURCES**

#### a) Overall Framing & Guidance

#### United Nations Children's Fund (UNICEF). 2022. UNICEF Fact Sheet: Children with Disabilities.

This fact sheet is aimed at policymakers, programmers, and advocates working to include children with disabilities in international development and humanitarian action. It provides a snapshot of the situation of children with disabilities and the main barriers they face in their daily lives based on available evidence. It is recognised that the available evidence is at times limited, particularly from the global south and in relation to certain topics such as climate change. The fact sheet is therefore not intended as a comprehensive review, but rather is a starting point for understanding why investing in inclusive policies and programmes can make a difference in the lives of children with disabilities, their families, and their communities.

#### United Nations Children's Fund (UNICEF). 2022.

E-Course Disability inclusion in Humanitarian Action.

This module sets out the key actions for coordination teams to ensure that the needs and priorities of persons with disabilities are addressed through humanitarian coordination. The module equips learners with the knowledge to identify the needs and priorities of persons with disabilities and to design and monitor a response that addresses these.

#### United Nations Children's Fund (UNICEF). 2017.

Including Children With Disabilities in Humanitarian Action: General guidance.

In addition to its sector-specific guidance notes, UNICEF's Including Children With Disabilities in Humanitarian Action series features a general guidance note. This note covers a range of actions and best practices to better include children and adolescents with disabilities in all stages of humanitarian action: across emergency preparedness, response and early recovery, and recovery and reconstruction.

#### The Alliance for Child Protection in Humanitarian Action. 2019. Minimum Standards for Child Protection in Humanitarian Action, 2019 Edition.

These inter-agency minimum standards create shared principles for those working in child protection. The standards aim to help humanitarian actors achieve high-quality child protection efforts. The framework helps support effective programming, advocacy, and communication, while strengthening coordination and accountability.

#### Inter-Agency Standing Committee (IASC). 2019.

Inclusion of Persons With Disabilities in Humanitarian Action.

These guidelines outline essential actions for humanitarian actors to both identify and respond to the needs of persons with disabilities in humanitarian settings and to effectively uphold their rights using relevant legal and policy frameworks. Included actions cover a range of sectors (education, mental health, and psychosocial support—or MHPSS, health) and span stages of humanitarian action (preparedness, response, and recovery).

#### b) Risk and Protective Factors

#### European Civil Protection and Humanitarian Aid Operations. 2019. The Inclusion of Persons With Disabilities in EU-funded Humanitarian Aid Operations.

This guidance note contains strategies and tools to ensure that obligations reflected in various frameworks (including the Humanitarian Aid Regulation, the 2007 EU Consensus on Humanitarian Aid, and the European Disability Strategy 2010–2020) can be realised in practice. The note aims to help shepherd participation of persons with disabilities in humanitarian programming. In addition, it aims to support mainstreamed interventions and services that effectively include persons with disabilities.

#### The Alliance for Child Protection in Humanitarian Action. 2021.

Why Identifying Risk and Protective Factors is a Critical Step in Prevention Programming: Implications for child protection in humanitarian action.

This brief provides decision-making guidance for population-level data collection regarding risk and protective factors to support effective prevention programming. The document provides an overview of critical, foundation terms—such as prevention, risk factor, and resilience—as well as a list of universal risk and protective factors that can be tailored based on context. In addition, it provides information on approaches for population-level data collection.

#### c) Inclusive Approaches & Data Collection in Action

#### United Nations Children's Fund (UNICEF). 2019.

Including Everyone: Strengthening the collection and use of data about persons with disabilities in humanitarian situations.

This guidance document explores the use and importance of disability-disaggregated data as well as humanitarian needs assessment frameworks and guidance as they relate to disability data disaggregation. The report provides four case studies featuring different humanitarian scenarios as they relate to data.

#### United Nations Children's Fund (UNICEF). New York, 2021. Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities.

Using the latest available data, this publication covers more than 60 indicators of child wellbeing, from nutrition and health, to access to water and sanitation, protection from violence and exploitation, and education. The report also includes the first ever global and regional estimates of children with disabilities.

CBM International, Humanity & Inclusion (HI) and the International Disability Alliance (IDA). 2019. Inclusion of Persons With Disabilities in Humanitarian Action.

These 39 case studies outline successes, challenges, and learnings regarding inclusion practices for persons with disabilities in humanitarian action and disaster risk reduction. The case studies cover 20 countries and reflect scenarios across all phases of humanitarian response.

#### **Women's Refugee Commission. 2014.** *Disability Inclusion: Translating policy into practice in humanitarian action.*

These findings come from a major study conducted by The Women's Refugee Commission regarding disability inclusion. Between 2011 and 2013, WRC conducted field visits with over 770 refugees and displaced persons across eight countries (India, Uganda, Thailand, Bangladesh, Nepal, Ethiopia, Philippines, and Lebanon). The report and its methodology provide a helpful potential model for how qualitative methods can be effectively utilised within large-scale data collection as well as relevant challenges and learnings from the study.

## **VI. APPENDICES**

#### a) Quantitative Assessment Methods

States that have ratified the Convention on the Rights of Persons with Disabilities are obligated to "collect appropriate information, including statistical and research data..." that is "disaggregated, as appropriate, and used to help assess the implementation of States Parties' obligations under the present Convention and to identify and address the barriers faced by persons with disabilities in exercising their rights."<sup>72</sup>

While qualitative methods remain a vital part of assessing risk/protective factors and needs for children with disabilities in humanitarian settings, several other methods and initiatives exist that can help complement qualitative data collected through the means described in this note. Examples of existing assessment methods include:

#### The Washington Group Short Set of Questions and The Washington Group/UNICEF Survey Module on Child Functioning

Designed by the Washington Group on Disability Statistics (part of the UN Statistical Commission), these question sets help identify adults (or, for the Survey Module on Child Functioning, children aged 2 to 17 years<sup>73</sup>) with disabilities on a national level.<sup>74</sup> Of importance, the Washington Group Questions have been successfully deployed in humanitarian settings to evaluate disability (measure prevalence, identify those at risk for exclusion, measure access) on a population-level;<sup>75</sup> for this reason, the tool has been given more attention here than others included below.

The Washington Group on Disability Statistics' Short Set on Functioning (WG-SS) centres around questions related to functioning within six basic and universal actions: seeing, hearing, walking, cognition, self-care, and communication<sup>76</sup> (while the Survey Module on Child Functioning judges difficulty across 14 domains).<sup>77</sup> The WG-SS is founded on the idea that, in an "unaccommodating" environment, limitations on these capabilities would restrict the individual's social participation—data analysis therefore aims to determine whether those identified to have difficulty within these six functions have participation rates (in realms like education, family life, etc.) equal to those who do not express limitations. The WG-SS uses the World Health Organization's International Classification of Functioning, Disability, and Health (ICF) as its conceptual foundation. Rather than a medical model of disability, the ICF utilises a bio-psychosocial model wherein disability is looked at as the interaction between a person's capabilities and environmental barriers.<sup>78</sup>

<sup>72</sup> United Nations, Convention on the Rights of Persons With Disabilities (New York: UN, 2006).

<sup>73</sup> United Nations Children's Fund, Including Children With Disabilities in Humanitarian Action: General Guidance (UNICEF, 2017).

<sup>74</sup> CBM International, Humanity & Inclusion, and the International Disability Alliance, Inclusion of Persons With Disabilities in Humanitarian Action (CBM International, HI, IDA, 2019).

<sup>75</sup> CBM International, Humanity & Inclusion, and the International Disability Alliance, Inclusion of Persons With Disabilities in Humanitarian Action (CBM International, HI, IDA, 2019).

<sup>76</sup> United Nations Children's Fund, Humanity & Inclusion, and the International Disability Alliance, *Including Everyone: Strengthening the Collection and Use of Data About Persons With Disabilities in Humanitarian Situations* (New York: UNICEF, 2019).

<sup>77</sup> United Nations Children's Fund, Including Children With Disabilities in Humanitarian Action: General Guidance (UNICEF, 2017).

<sup>78</sup> Washington Group on Disability Statistics, *The Washington Group Short Set on Functioning* (Washington Group on Disability Statistics, 2017).

The WG-SS is intended for use on national censuses and surveys and designed to produce data comparable for populations cross-nationally. The results are able to represent the majority of (though of course not all) persons with limitations within the selected arenas and reflect the most common forms of these limitations.

#### Conducting the WG-SS goes as follows:79

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?
- 2. Do you have difficulty hearing, even if using a hearing aid?
- 3. Do you have difficulty walking or climbing steps?
- 4. Do you have difficulty remembering or concentrating?
- 5. Do you have difficulty (with self-care such as) washing all over or dressing?
- 6. Using your usual language, do you have difficulty communicating, (for example understanding or being understood by others)?

Each question then has four possible responses, which are read after each inquiry:

- 1. No, no difficulty
- 2. Yes, some difficulty
- *3. Yes, a lot of difficulty*
- 4. Cannot do it at all

More information about the WG-SS, including implementation materials ("Translation of the Washington Group Tools," "Analytic Guidelines," and guidelines related to modifying the WG-SS module) can be found via the Washington Group website: <u>https://www.washingtongroup-disability.com/</u>.

#### The Model Disability Survey (MDS)

A survey tool developed by the World Health Organization and the World Bank that examines population levels of disability and severity as well as needs and barriers experienced by persons with disabilities.<sup>80</sup>

#### UNICEF's Multiple Indicator Cluster Surveys Programme (MICS)

The "largest source of statistically sound and internationally comparable data on children and women worldwide."<sup>81</sup> Through the programme, country-specific survey designs are created based on an initial gap assessment undertaken by the Global MICS Team, the country's UNICEF offices, and country-level government; based on its findings, a trained team then conducts face-to-face household interviews to gain whatever data is determined to be most vital based on context.<sup>82</sup>

<sup>79</sup> Washington Group on Disability Statistics, *The Washington Group Short Set on Functioning* (Washington Group on Disability Statistics, 2017).

<sup>80</sup> World Health Organization, "Disability: Model Disability Survey – Questions and Answers," <u>https://www.who.int/news-room/guestions-and-answers/item/model-disability-survey</u>, November 27, 2020.

<sup>81</sup> United Nations Children's Fund, "About MICS," <u>https://mics.unicef.org/about</u>, accessed July 25, 2022.

<sup>82</sup> United Nations Children's Fund, "MICS6 Tools," <u>https://mics.unicef.org/tools#survey-design</u>, accessed July 25, 2022.

Starting in 2016, the Child Functioning Module and the Washington Group Short Set on Functioning7 became part of the MICS and are used to collect data on children aged 2 to 17 years and on adult women and men aged 18 and older, respectively. With the inclusion of these two tools, the MICS programme has become the largest source of internationally comparable data on children and adults with disabilities. When analysed in conjunction with other MICS indicators, the data can be used to document the inequities experienced by persons with disabilities at the global level.<sup>83</sup>

#### The Demographic and Health Surveys (DHS) Programme

The programme collects and analyses quantitative and/or quantitative (depending on countryspecific need), representative, population-level data regarding health, nutrition, and more, including dynamics on topics like reproductive health, HIV/AIDS, and family planning, and cultural practices that might affect health (such as female genital cutting).<sup>84 85</sup>

#### b) Minimum Standards for Child Protection in Humanitarian Action – Recommendations for Further Inclusion of Children with Disabilities

The *Minimum Standards for Child Protection in Humanitarian Action* is a critical document: these inter-agency minimum standards (first produced in 2012 and then updated in 2019) create shared principles for those working in child protection, improving both the quality of programming and related advocacy and communication, while strengthening coordination and accountability. The document is built around 10 principles, each of which includes a robust set of standards:

- Survival and development
- Non-discrimination and inclusion
- Children's participation
- The best interests of the child
- Enhance people's safety, dignity, and rights and avoid exposing them to further harm
- Ensure people's access to impartial assistance according to need and without discrimination
- Assist people to recover from the physical and psychological effects of threatened or actual violence, coercion, or deliberate deprivation
- Help people to claim their rights
- Strengthen child protection systems
- Strengthen children's resilience in humanitarian action

The *Minimum Standards* note from the start that "humanitarian actors must promote the inclusion of children of all genders, ages and disabilities and adapt programming to children's evolving capacities and needs."<sup>86</sup> In addition, children with disabilities are included outright in a number of places and, critically, are noted as a subcategory of children that likely have particular and more intensive child protection needs.

<sup>83</sup> United Nations Children's Fund, <u>Seen, Counted, Included: Using data to shed light on the well-being of children with disabilities</u>, UNICEF, New York, 2021, p.10.

<sup>84</sup> The DHS Program, "Home Page," <u>https://dhsprogram.com/</u>, accessed July 25, 2022.

<sup>85</sup> The DHS Program, "Qualitative Research," <u>https://dhsprogram.com/Methodology/Survey-Types/Qualitative-Research.cfm</u>, accessed July 25, 2022.

<sup>86</sup> The Alliance for Child Protection in Humanitarian Action, *Minimum Standards for Child Protection in Humanitarian Action*, 2019 Edition (The Alliance for Child Protection in Humanitarian Action, 2019).



Several of the concepts outlined in this note—namely, the importance of context in defining disability and identifying risk and protective factors for children with disabilities, universal design, and the accessibility continuum—could allow the document to offer more nuanced and potentially impactful guidance regarding children with disabilities. Adding (or in some cases, expanding) these concepts within both the document's introductory sections and overarching principles could, in particular, provide a more specific yet more holistic understanding of what "access" means.

For example, the concept of universal design could be useful to consider in Principles 4 ("the best interests of the child") and 8 ("help people to claim their rights"). Both note the tactic of providing information to children as key to bringing them in as active participants and also empowering them as rights holders. However, for children with disabilities, it is critical to articulate that this information must be fully accessible for a wide spectrum of disability types for them to receive it, process it, and use it for their own protection and self-advocacy.

The Minimum Standards could also more strongly emphasise the importance of context and its influence on the cultural definition of "disability." The document notes that the standards must be "adapted, or 'contextualised', to the relevant context,"<sup>87</sup> including adding or prioritising key actions accordingly. However, a fuller introductory note could be added about the ways that context is particularly important in terms of defining disability, and how that contextual definition may shape the relevant risk and protective factors for children with disabilities in the humanitarian crisis, and thus their child protection needs.

Relatedly, when the Minimum Standards explore "environmental considerations,"<sup>88</sup> it could extend this idea to go beyond the physical environment (ex. "disasters, climate change, noise and

<sup>87</sup> The Alliance for Child Protection in Humanitarian Action, *Minimum Standards for Child Protection in Humanitarian Action*, 2019 Edition (The Alliance for Child Protection in Humanitarian Action, 2019).

<sup>88</sup> The Alliance for Child Protection in Humanitarian Action, *Minimum Standards for Child Protection in Humanitarian Action*, 2019 Edition (The Alliance for Child Protection in Humanitarian Action, 2019).

air pollution can make children and families more vulnerable as they can lead to or worsen forced displacement and migration, gender inequities, livelihood insecurity and health hazards").<sup>89</sup> Environmental considerations could also include the lived sociocultural and socioeconomic environment, particularly in terms of attitudes towards disability and children with disabilities that might create or exacerbate risk factors and vulnerabilities.

Expanded reference within the principles themselves to the attitudinal factors that can shape treatment of and access for children with disabilities could also help widen the document's definition of inclusion—recognising the important role beliefs play in discrimination and that, therefore, a critical component of humanitarians' responsibility to "identify and monitor existing and new patterns of discrimination, power and exclusion"<sup>90</sup> is working to shift the attitudes and perspectives that undergird discrimination within each humanitarian context.

#### c) The Importance of Cross-Sectoral Responses

When devising response strategies that promote the protection of children with disabilities in humanitarian contexts, it's important to consider the ways in which multiple factors interact and have an impact. Everything from genetics to societal attitudes can affect a child. A growing body of research supports the ways in which a multitude of factors can lead to negative outcomes, including poverty, discrimination, environmental toxins, poor nutrition. They are all stressors that can cause significant adversity and, in turn, lead to chronic impairments.<sup>91</sup>

This dynamic interplay between a wide range of factors requires dynamic interplay between relevant sectors. Linking and coordinating services can drastically reduce stress on children and their families,<sup>92</sup> which can have wide-reaching impacts. Furthermore, cross-sectoral collaboration that thoughtfully responds to child protection needs leads to higher-quality positive outcomes for children. Conversely, siloed responses that fail to consider child protection can lead to inefficiencies and even potentially increased harm for children,<sup>93</sup> while also risk excluding children with disabilities entirely.

Below is a table (adapted from UNICEF's guidance series, *Including Children with Disabilities in Humanitarian Action*) that outlines some ways in which a variety of sectors intersect with children with disabilities in humanitarian settings. Included is information not only on the importance of each sector to the protection of a child with disabilities and their family, but common risks that can lead to children with disabilities being excluded from that sector's work. To combat this, the table offers some examples of ways to effectively incorporate children with disabilities into existing sectoral programmes and services ("mainstreaming") as well as ideas to create specialised programming targeted towards this population. Finally, it provides a few case examples to exemplify these approaches in action.

The guidance in the table can be used by child protection actors to reflect on how best to approach mainstreaming of protection for children with disabilities, and/or integrated programming for children with disabilities, with other sectors.

<sup>89</sup> The Alliance for Child Protection in Humanitarian Action, *Minimum Standards for Child Protection in Humanitarian Action*, 2019 Edition (The Alliance for Child Protection in Humanitarian Action, 2019).

<sup>90</sup> The Alliance for Child Protection in Humanitarian Action, *Minimum Standards for Child Protection in Humanitarian Action*, 2019 Edition (The Alliance for Child Protection in Humanitarian Action, 2019).

<sup>91</sup> Jack P. Shonkoff et al., "Leveraging the Biology of Adversity and Resilience to Transform Pediatric Practice," *Pediatrics* 147, no. 2 (2021), https://doi.org/10.1542/peds.2019-3845.

<sup>92</sup> Jack P. Shonkoff et al., "Leveraging the Biology of Adversity and Resilience to Transform Pediatric Practice," *Pediatrics* 147, no. 2 (2021), https://doi.org/10.1542/peds.2019-3845.

<sup>93</sup> The Alliance for Child Protection in Humanitarian Action, *Minimum Standards for Child Protection in Humanitarian Action*, 2019 Edition (The Alliance for Child Protection in Humanitarian Action, 2019).

## Overview of Cross-Sector Challenges and Opportunities for Including Children with Disabilities\*

	Wash <sup>94</sup>	Education <sup>95</sup>	Health <sup>96</sup>	Nutrition <sup>97</sup>
Impact on Children with Disabilities	Facilities that do not take into consideration the needs of children with disabilities may threaten their privacy – and therefore potentially their safety and dignity – especially for girls with disabilities regarding menstruation. Inaccessible facilities/ programmes may create additional responsibilities for caregivers of children with disabilities.	Children with disabilities are excluded from education at higher rates, especially in emergencies – this is true even more so for displaced children with disabilities and girls with disabilities. Because of this increased educational exclusion, children with disabilities also have a higher likelihood of missing out on critical information and services (related to WASH, health, and nutrition, for example) that is often provided in educational settings.	Increased risk of psychosocial disorders or worsened pre-existing conditions for children with disabilities. Increased risk of violence and sexual violence for children with disabilities, particularly for girls with disabilities, that can lead to HIV, other sexually transmitted diseases, and injury.	A "cycle of malnutrition," wherein disability can lead to malnutrition (difficulty swallowing, absorbing nutrients, etc.), and malnutrition can also cause further and/or new disabilities. Lack of adequate caregiver knowledge can lead to malnutrition for children with disabilities, as can larger stigmas and discrimination.
Mhat Leads to Exclusion for Children with Disabilities	Information on WASH and other related topics not being offered in a range of formats or conveyed in a range of settings	Parents (due to stigma) keeping children with disabilities hidden away or not recognising the importance of education for children with	Data in health information systems not being reliable and/or disaggregated regarding disability.	Food distribution sites (and/or health facilities that provide nutrition) being inaccessibly located.
	outside traditional learning environments (where children with disabilities, especially in emergencies, often have less access).	disabilities, reducing their participation. Children with disabilities being excluded from or made to feel unwelcome at child-friendly	Lack of training across health care personnel hindering their ability to interact with and help children with disabilities. Incorrect beliefs	Nutrition personnel/ professionals being unable to communicate with children and/ or caregivers with disabilities.
What L Child	WASH staff incorrectly assume that it is too expensive to make WASH infrastructure fully accessible.	spaces and temporary education environments. Teachers lacking the ability to teach children	leading to inadequate information regarding sexual relations and safe sex being shared with persons with disabilities.	Distributed food not being appropriate for children who need modified food consistency.

<sup>94</sup> United Nations Children's Fund, Including Children with Disabilities in Humanitarian Action: WASH (UNICEF, 2017).

<sup>95</sup> United Nations Children's Fund, Including Children with Disabilities in Humanitarian Education (UNICEF, 2017).

<sup>96</sup> United Nations Children's Fund, Including Children with Disabilities in Humanitarian Action: Health and HIV/AIDS (UNICEF, 2017).

<sup>97</sup> United Nations Children's Fund, Including Children with Disabilities in Humanitarian Action: Nutrition (UNICEF, 2017).

	Wash <sup>94</sup>	Education <sup>95</sup>	Health <sup>96</sup>	Nutrition <sup>97</sup>
What Leads to Exclusion for Children with Disabilities	Long lines and wait times at distribution sites making them unwelcoming for children with disabilities and their families. WASH supply distribution not including accessible toilets, hygiene kits, and other supplies for children with disabilities.	with disabilities, or school infrastructure, materials, or transportation being inaccessible.	Information regarding health – including available services – not being offered via a range of accessible channels/formats.	Nutrition programmes being located primarily in schools – where children with disabilities have a lower likelihood of being included, particularly in emergencies – and other institutions being overlooked for these services.
Example Action: Incorporating Children with Disabilities into Existing Programmes	Offer staff of WASH programmes training on hygiene and self- care needs for children with disabilities – skills like how to transfer a child from a wheelchair to toilet chair/accessible toilet, how to physically support a child who has trouble sitting independently, etc.	Support governments in building capacity for teacher training (pre- service and in-service) that will allow them to provide inclusive instruction (including adapting their communication style and providing more flexible instruction in the classroom).	Develop health-related information (including that related to HIV/ AIDS prevention and other services) in at least two formats.	Certain measurements to ascertain malnourishment are misleading for particular children with disabilities (e.g., mid-upper arm circumference may not be accurate for wheelchair users who have built up upper arm muscles), leading to children not being accurately identified as needing supports – create alternative measurement methods, including visual assessment and/or lower leg length, when standard malnutrition measurements might be misleading.
Example Action: <b>Targeting</b> <b>Programmes to Children</b> with Disabilities	Create alternative toilet options for children who have difficulty reaching WASH facilities.	Create itinerant teaching programmes, such as home-based or mobile education programmes for displaced children or those who can't otherwise reach educational spaces.	Bring sexual and reproductive health programmes and services to children located in special schools and residential facilities.	Provide nutrition programmes targeted to institutions outside of traditional schools, such as residential institutions and/or orphanages.

	Wash <sup>94</sup>	Education <sup>95</sup>	Health <sup>96</sup>	Nutrition <sup>97</sup>
Relevant Example in Practice	Iraq: children and adults with disabilities (as well as other older adults) expressed a need for and lack of access to diapers. Handicap International undertook group interviews to identify affected families who could not afford disposable diapers and provided guidance for a tailor, who then made reusable diapers for families (two diapers and 20 cotton inserts each). In addition, the group provided training for recipient families on how to launder and care for the diapers: in some camps, Action Against Hunger provided hot water tanks to this end.	The State of Palestine: teachers in Rafah and Gaza cities were offered a training course on inclusive and adapted teaching methods as well as guidance on "inclusion links" – activities to facilitate interaction between students at special and regular schools as well as exchange between the teachers.	The Philippines: following Typhoon Haiyan in 2013, an international organisation trained and worked with local physical therapists to distribute wheelchairs, including checking for appropriate fit and providing guidance for recipients on how to use and maintain them.	Bangladesh: the World Food Programme prioritises persons with disabilities (as well as pregnant women and elderly individuals) in its food distribution, while also covering transportation costs to deliver food to those who cannot reach the sites.

\*In addition to the sectors included in the table above, the series also includes a guidance note dedicated specifically to child protection, which can provide additional reading on this topic.





