

# Exclusive humanitarianism: Policy recommendations for genuine inclusion of persons with disabilities in humanitarian action

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## Abstract

*The challenge faced by Somalia's newly established National Disability Agency (NDA), along with other emerging actors in the disability arena, is how to address the perception that disability is primarily a humanitarian issue in a country that not only is in conflict but also faces cyclical humanitarian crises. A further challenge for the NDA is how to ensure that the humanitarian architecture put in place facilitates non-discrimination, as well as the inclusion of and participation by persons with disabilities. While a typical humanitarian architecture can inadvertently reinforce an already stigmatizing charity or welfare approach towards persons with*

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*disabilities, Somalia's experience demonstrates that humanitarian actors can do a lot with leadership, a willingness to leave agency branding behind, and an active committed partner such as the NDA. Nevertheless, genuine inclusion in Somalia's overall State-building project needs also to be the remit of development, reconciliation and similar actors, with access to and participation of persons with disabilities guaranteed in their range of processes and frameworks.*

**Keywords:** Somalia, disability, UN Convention on the Rights of Persons with Disabilities, armed conflict, humanitarian action, Washington Group Questions.

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## Introduction

Many countries in conflict face routine humanitarian crises. The use of a humanitarian-dominated approach in a conflict setting necessarily affects State priorities as well as how the State relates to its citizens through service provision, development opportunities, political space and so forth. In addition, the humanitarian paradigm impacts how, and which, international actors engage with the given State.

Given the historical medical and charity approaches to disability,<sup>1</sup> this context can, and does, influence how disability issues are handled in humanitarian operations that have an armed conflict dimension. This paper seeks to explore the extent to which a humanitarian-focused framework facilitates or inhibits inclusion of and participation by persons with disabilities. It asks whether the existence of armed conflict exacerbates this dynamic, acknowledging that armed conflict is fluid, frequently changing in intensity, tempo and geographical coverage. This latter point also means that State-building, development and reconciliation initiatives inevitably take place against this backdrop. As such, a third consideration that will be explored is how much the absence of a defined aftermath to a conflict affects the inclusion of disability voices in the reconciliation, development and State-building agendas.

1 Office of the UN High Commissioner for Human Rights (UN Human Rights), *Convention on the Rights of Persons with Disabilities Advocacy Toolkit*, Professional Training Series No. 15, HR/P/PT/15, 2008, available at: [www.ohchr.org/sites/default/files/Documents/Publications/AdvocacyTool\\_en.pdf](http://www.ohchr.org/sites/default/files/Documents/Publications/AdvocacyTool_en.pdf) (all internet references were accessed in July 2022) (describing the UN Convention on the Rights of Persons with Disabilities as a “paradigm shift in the treatment of persons with disabilities from a medical or charity perspective to a rights-based approach”). The World Humanitarian Summit’s Agenda for Humanity also focused on this, albeit more broadly for the humanitarian sphere. One author has written that the Agenda “requires us to place equality and solidarity at the heart of our decision making processes, and remove the notion of ‘charity’. Putting communities in the driving seat brings back their dignity in the midst of crisis. It also opens space for meaningful dialogue between humanitarians and vulnerable people on addressing needs; improves accountability; and crucially, shifts the power dynamic that is perpetuated by perceptions of international humanitarianism being the ‘rescuers’ of vulnerable communities.” Paul Murphy, “Humanitarian Reform Must Be a Collective Endeavour”, *Safer World Blog*, 19 August 2018, available at: [www.saferworld.org.uk/resources/news-and-analysis/post/786-humanitarian-reform-must-be-a-collective-endeavour](http://www.saferworld.org.uk/resources/news-and-analysis/post/786-humanitarian-reform-must-be-a-collective-endeavour).

The experience of Somalia will be used to illustrate these points. Somalia has lurched from one humanitarian crisis to another and continues to deal with conflict and terrorism. Despite this, Somalia has made efforts to reinforce its human rights framework within the broader State-building process, including with the ratification of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD) in 2019. Showing its commitment to the issue, the Somali government quickly passed legislation to establish a National Disability Agency, which has a broad promotional and representational mandate, as well as data collection and management and resource mobilization. The challenge that the NDA and other emerging actors in the disability arena will face is how to navigate the long-standing humanitarian framework, a civil war legacy and ongoing conflict and terrorism.

## The Somali context

Somalia gained independence in 1960, forming a unitary system of government. In 1969, the Somali Republic's second president, Abdirashid Ali Sharmake, was assassinated, and Siad Barre, a military officer, took power on 21 October in what is referred to as a bloodless revolution.<sup>2</sup> Siad Barre suspended the Constitution and initially governed through the twenty-five-member Supreme Revolutionary Council, renaming the country the Somali Democratic Republic. His governance became increasingly repressive and brutal,<sup>3</sup> leading to a loose alliance of opposition groups overthrowing him. This alliance did not survive, however, resulting in a civil war breaking out in the early 1990s. The subsequent two decades were marked by warlordism, clan conflict, governance by the Islamic Courts Union, and the emergence of Al-Shabaab. A Transitional Federal Government was formed in 2004 in Kenya, paving the way for the establishment of the Federal Government of Somalia in 2012. Prior to the government's return to Somalia, famine was declared in 2011, leading to significant displacement and a reported 260,000 deaths. Since 2012, key governmental priorities have included the implementation of federalism, a process that is still under way. While five federal member States have been created, certain boundaries remain undelimited.<sup>4</sup> In addition, the Constitution, which would provide the contours of power-sharing and resolve some outstanding federalism questions, remains provisional and under review. At the time of writing, Somalis are facing a drought and possibly an impending famine, having only just emerged from a 2017 drought, floods in 2019, locust invasions in 2019 and 2020, and of course the COVID-19 pandemic.

The extended periods of conflict and political instability have resulted in Somalia continuing to rely heavily on humanitarian assistance to respond to the conflicts, the effects of warfare, cyclical droughts, floods, and climate change-induced degradation, which is increasingly affecting livelihoods, further exacerbating displacement.

2 Helen Chapin Metz (ed.), *Somalia: A Country Study*, Library of Congress, Field Research Division, 1993.

3 Africa Watch, *Somalia: A Government at War with Its Own People*, London, January 1990.

4 The region of Somaliland self-declared independence on 18 May 1991 following the collapse of President Siad Barre's regime. This self-declaration is not internationally recognized.

## Historical approach to disability

Historically, the Somali Ministry of Labour and Social Affairs (MoLSA) led disability-related initiatives. With the destruction of government archives,<sup>5</sup> however, information on how disability was addressed is limited. Nevertheless, in discussions with Somalis, it is evident that disability was understood as a social welfare issue in line with then president Siad Barre's scientific socialism as well as the global approach to disability in the 1980s. For example, graduates from a Mogadishu-based vocational school for men with disabilities were employed in government institutions. During this time, the Somali Disability Cooperative was established to advocate for the inclusion of people with disabilities, with government support.<sup>6</sup>

While the number of people injured and killed in conflict-related incidents is known, the psychological impact of over 30 years of war in Somalia has not been measured.<sup>7</sup> As is typical in war zones, disabled former combatants in Somalia often actively contribute to advocacy, albeit more with a focus on acquired disabilities (and challenges around gender in a patriarchal society). For example, in Mogadishu during the 1980s, the government implemented a housing project for former military personnel who had become disabled while serving. Shops and offices for rent and a popular cinema were part of this project to generate income for these military personnel.<sup>8</sup>

## Legal and policy frameworks

With the establishment of a Federal Government in Mogadishu in 2012, a Provisional Constitution of the Federal Republic of Somalia was drafted. It explicitly guarantees Somali citizens with disabilities equal rights before the law,<sup>9</sup> and creates a positive obligation in terms of economic and social rights – it ensures that persons with disabilities “who have suffered discrimination get the necessary support to realise their socio-economic rights”.<sup>10</sup> A National Council on Disability was formed in

5 Mohamed Trunji, *Somalia: The Untold History 1941–1969*, Looh Press, Leicester, 2015, p. xxvi, notes that “[r]egrettably, it has not been possible to consult the many important documents kept in government offices in Somalia before the civil war, which, whether intentionally or unintentionally, were destroyed by the gangs who occupied Mogadishu and other major urban centres at the beginning of 1991.”

6 See the Somali Disability Cooperative Facebook page, available at: [www.facebook.com/isikaasha\\_tadanaafada/](http://www.facebook.com/isikaasha_tadanaafada/). The chairperson, Warsame Abdhullahi (known by the nickname “Indhole”, meaning “blind”), was able to influence the then president, Siad Barre, and has been credited by some with the achievements in disability inclusion that took place during that time.

7 Human Rights Watch, *Human Rights Watch World Report 1993–Somalia*, 1 January 1993, available at: [www.refworld.org/docid/467fca601e.html](http://www.refworld.org/docid/467fca601e.html) (stating that “[b]etween November 1991 and February 1992, Africa Watch and Physicians for Human Rights documented 14,000 people were killed and 27,000 injured in Mogadishu. An unknown number were permanently disabled. Tens of thousands more were psychologically scarred and will suffer from post-traumatic stress disorder and varieties of pathological grief, not only because of the horrors they have suffered, but also because of the failure to observe traditional rituals to respect the dead”).

8 Interview with key informant, 6 April 2022.

9 Provisional Constitution of the Federal Republic of Somalia, 2012, Art. 11(1): “All citizens, regardless of sex, religion, social or economic status, political opinion, clan, *disability*, occupation, birth or dialect shall have equal rights and duties before the law” (emphasis added).

10 *Ibid.*, Art. 27(5).

2012 with the role of mainstreaming disability into government policy. The Council, an umbrella platform of representatives from various disability groups, was linked to MoLSA.<sup>11</sup> Also, in 2012 Somalia became the 160th party to the Convention on the Prohibition of the Use, Stockpiling, Production and Transfer of Anti-Personnel Mines and on Their Destruction, or Ottawa Convention.<sup>12</sup>

The Ministry of Women and Human Rights Development (MoWHRD) was established under the 2012 government and became operational in 2013. The MoWHRD's broad mandate includes promotion and protection of the rights of persons with disabilities, which were factored into the first Human Rights Road Map adopted in 2013. In 2015, Somalia became party to the UN Convention on the Rights of the Child, providing a basis for advocacy on children with disabilities. In 2017, the then minister for women and human rights development prioritized disability with the launch of the National Disability Road Map, entitled "Inclusion of Persons with Disabilities and Disability Rights in Governance and Development Processes (2017–2019)".<sup>13</sup> Following the Ministry's consultations with Somali organizations of persons with disabilities (OPDs),<sup>14</sup> three priorities were set: first, adoption of a comprehensive law on disability; second, establishment of a National Disability Agency (NDA); and third, ratification of the UNCRPD.<sup>15</sup> By 30 December 2018, the federal president of Somalia had signed the bill on the NDA into law and in August 2019, Somalia became the 178th party to the UNCRPD. The ratification of the UNCRPD, the UN Convention on the Rights of the Child and the Ottawa Convention complement Somalia's treaty obligations dating from prior to the civil war, which include the International Covenant on Civil and Political Rights, the International Covenant on Economic, Social and Cultural Rights, the Convention Against Torture, and the Convention on the Elimination of All Forms of Racial Discrimination. A draft Disability Rights Bill is with the Cabinet, and it is hoped that it will be a priority for Somalia's 11th Parliament.

## The situation of persons with disabilities

The number of persons with disabilities in Somalia is unclear,<sup>16</sup> with the World Health Organization/World Bank global estimate of 15%<sup>17</sup> being used as the basis

11 Swedish International Development Agency (SIDA), *Disability Rights in Somalia*, 2014, p. 2, available at: <https://cdn.sida.se/app/uploads/2021/05/07125817/rights-of-persons-with-disabilities-somalia.pdf> (noting that no budget had been provided).

12 See the Ottawa Convention website's page for Somalia, available at: <https://new.apminebanconvention.org/en/membership/somalia/>.

13 The MoWHRD has developed a subsequent Road Map for 2020–23.

14 MoWHRD, *Rapid Assessment of the Status of Children with Disabilities in Somalia*, 2020, available at: [https://mwhrd.gov.so/en/wp-content/uploads/2020/09/Rapid-Assessment-Children-with-Disabilites-in-Somalia\\_Report\\_FA\\_Digital-1-1.pdf](https://mwhrd.gov.so/en/wp-content/uploads/2020/09/Rapid-Assessment-Children-with-Disabilites-in-Somalia_Report_FA_Digital-1-1.pdf). The minister acknowledged that the extensive progress made would not have been possible without the determination and advocacy of Somalis with disabilities and their representative organizations.

15 Convention on the Protection and Promotion of the Rights and Dignity of Persons with Disabilities, UNGA Res. 61/106, 13 December 2006 (entered into force 3 May 2008).

16 SIDA, above note 11 (noting that "[t]here are no reliable statistics of prevalence of disabilities in the Somali population").

17 World Bank, "Disability Inclusion", available at: [www.worldbank.org/en/topic/disability](http://www.worldbank.org/en/topic/disability).

for Somalia's Humanitarian Needs Overview as well as other strategies and plans that require figures on disability.<sup>18</sup> It has nevertheless been acknowledged that the percentage is likely to be higher due to the legacy of war, which includes the collapse of the health system.<sup>19</sup>

While the normative building blocks for disability rights have been put rapidly in place, implementation has not been at a commensurate pace. As the *Somalia 2021 Human Rights Report* by the US Department of State notes:

The law provides equal rights before the law for persons with disabilities and prohibits the state from discriminating against them. Authorities did not enforce these provisions, and disability rights organizations reported a widespread lack of equal access to education, health services, public buildings, and transportation.<sup>20</sup>

Similarly, Amnesty International has concluded in a report on Somalia that “the rights of most people with disabilities continue to be excluded, and their particular needs and concerns forgotten”.<sup>21</sup>

At the societal level, a 2019 Disability Assessment conducted by UN Human Rights in Somalia found that persons with disabilities are subjected to a range of stereotypes, including regarding a person with a specific impairment as disabled in his or her entirety.<sup>22</sup> That being said, disability tends to be associated with physical impairments. This necessarily impacts inclusion of all persons with disabilities, particularly invisible disabilities.<sup>23</sup> Somalis with psycho-social or intellectual disabilities face the challenge of a specific set of cultural beliefs and stereotypes. For example, some Somalis believe that mental disabilities come from evil spirits or the evil eye<sup>24</sup> and that Somalis with such disabilities are not part of society.<sup>25</sup>

There are a range of reasons why progress in implementing legal and policy frameworks has not been made. The 10th Parliament's term expired in December 2020, and a drawn-out electoral process prevented the new Parliament from being established until June 2022. This has affected investment in development,

18 UN Office for the Coordination of Humanitarian Affairs (OCHA), *Humanitarian Needs Overview Somalia: Humanitarian Programme Cycle 2022*, October 2021, available at: <https://tinyurl.com/2y8777kh>.

19 SIDA, above note 11.

20 US Department of State, Bureau of Democracy, Human Rights and Labour, *Somalia 2021 Human Rights Report*, 12 April 2022, p. 43, available at: [www.state.gov/wp-content/uploads/2022/02/313615\\_SOMALIA-2021-HUMAN-RIGHTS-REPORT.pdf](http://www.state.gov/wp-content/uploads/2022/02/313615_SOMALIA-2021-HUMAN-RIGHTS-REPORT.pdf).

21 Amnesty International, *Somalia: Prioritise Protection for People with Disabilities*, 12 March 2015, p. 18, available at: [www.amnesty.org/en/wp-content/uploads/2021/05/AFR5211662015ENGLISH.pdf](http://www.amnesty.org/en/wp-content/uploads/2021/05/AFR5211662015ENGLISH.pdf).

22 UNSOM Human Rights and Protection Group (HRPG) and UN Human Rights, *Situation Analysis of Persons with Disabilities in Somalia*, 2019. On file with author.

23 Brigitte Rohwerder, *Disability in Somalia*, K4D Helpdesk Report, Institute of Development Studies, Brighton, 19 January 2018, p. 2, available at: <https://tinyurl.com/y2ekbcbp>.

24 Human Rights Watch, “Chained Like Prisoners”: *Abuses against People with Psychosocial Disabilities in Somaliland*, 2015, p. 24, available at: [www.hrw.org/report/2015/10/25/chained-prisoners/abuses-against-people-psychosocial-disabilities-somaliland](http://www.hrw.org/report/2015/10/25/chained-prisoners/abuses-against-people-psychosocial-disabilities-somaliland).

25 Aragsan Samatar, *Somali Parents and Their Perceptions of the Autism Spectrum Disorder Diagnosis*, St Catherine University Repository, Sophia, 2016, available at: [https://sophia.stkate.edu/cgi/viewcontent.cgi?article=1668&context=msw\\_papers](https://sophia.stkate.edu/cgi/viewcontent.cgi?article=1668&context=msw_papers).

and advocacy attention has turned elsewhere. An added factor is another unfolding humanitarian crisis, in the form of an extreme drought, which requires prioritization.<sup>26</sup>

## Humanitarianism in a protracted crisis setting

### The humanitarian apparatus: Promoting inclusion, minimizing exclusion

The main objective of humanitarian assistance is to address acute rather than chronic needs, often framed as saving lives at immediate risk.<sup>27</sup> However, this has changed globally, with terms such as “protracted” and “cyclical” being commonly ascribed to a range of humanitarian operations.<sup>28</sup> There has been a corresponding “rapid expansion of an organised humanitarian system” consisting of mechanisms, normative frameworks, policies and procedures coordinated through “diverse institutions that comprise what in some ways has become the world’s humanitarian welfare system”.<sup>29</sup> Somalia is an example of this. The historical presence and role of humanitarian assistance, which government services have not yet replaced, means that humanitarian actors are engaged in the delivery of basic services such as health care, nutrition and education, food and water, and social protection.<sup>30</sup>

26 At the timing of writing, Somalia had “confirmed pockets of catastrophic food insecurity”. This means that the affected population have extreme critical levels of acute malnutrition and mortality, a situation identified by the Integrated Food Security Phase Classification (see below note 60) as a Famine (Phase 5). See OCHA, *Somalia: Drought Response and Famine Prevention*, Situation Report No. 8, 30 June 2022, available at: <https://reliefweb.int/report/somalia/somalia-drought-response-and-famine-prevention-situation-report-no-8-30-june-2022>.

27 International Committee of the Red Cross and International Federation of Red Cross and Red Crescent Societies, “Code of Conduct for the International Red Cross and Red Crescent Movement and Non-Governmental Organizations (NGOs) in Disaster Relief”, available at: [www.icrc.org/en/doc/assets/files/publications/icrc-002-1067.pdf](http://www.icrc.org/en/doc/assets/files/publications/icrc-002-1067.pdf).

28 Sarah Dalrymple and Amanda Thomas, *Supporting Longer Term Development in Crises at the Nexus: Lessons from Somalia*, February 2021, p. 50, available at: [https://reliefweb.int/sites/reliefweb.int/files/resources/Supporting\\_longer\\_term\\_development\\_in\\_crises\\_at\\_the\\_nexus\\_Lessons\\_from\\_Somalia.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/Supporting_longer_term_development_in_crises_at_the_nexus_Lessons_from_Somalia.pdf) (stating that “[i]nterviewees unanimously argue that a crisis is not a crisis if it happens every year”); Marc DuBois, *The New Humanitarian Basics*, Humanitarian Policy Group Working Paper, May 2018, p. 8, available at: <https://cdn.odi.org/media/documents/12201.pdf> (stating that the term “protracted crisis” is an oxymoron); Alfonso Medinilla, Lidet Tadesse Shiferaw and Pauline Veron, *Think Local: Governance, Humanitarian Aid, Development and Peacebuilding in Somalia*, Discussion Paper No. 246, March 2019, p. 9, available at: <https://ecdpm.org/wp-content/uploads/DP246-march-2019-think-local-Governance-humanitarian-aid-development-peacebuilding-Somalia-ECDPM1.pdf> (stating that “Somalia is a good example of a country in which a state of crisis has become the norm”).

29 Norah Niland, Riccardo Polastro, Antonio Donini and Amra Lee, *Independent Whole of System Review of Protection in the Context of Humanitarian Action*, Norwegian Refugee Council, May 2015, p. 16, available at: [https://reliefweb.int/sites/reliefweb.int/files/resources/final\\_whole\\_of\\_system\\_report.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/final_whole_of_system_report.pdf).

30 Christina Bennett and Matthew Foley, *Time to Let Go: Remaking Humanitarian Action for the Modern Era*, Humanitarian Policy Group, Overseas Development Institute, March 2016, p. 35, available at: <https://cdn.odi.org/media/documents/10422.pdf> (stating that “in protracted crises, humanitarian activities – and aspirations – have, by default, expanded into recovery and basic service provision, including long-term health, nutrition and education, food assistance, livelihoods support and social protection measures”).

For Somalia, this has meant that “humanitarian aid has become an essential part of the service delivery model” over the long term.<sup>31</sup> As such, much service delivery is dependent on annualized funding; it is needs-based rather than rights-based. This paradigm should also be considered in the context of how humanitarian assistance has historically operated in Somalia. While the intent is “to alleviate immediate suffering, [humanitarian assistance] has also unwittingly reinforced abusive structures by failing to take into account the political economy of marginalization”.<sup>32</sup> This was acknowledged in Somalia’s 2022 Humanitarian Response Plan, which noted that “[p]eople with disabilities in Somalia face additional barriers and risks, and are often excluded from humanitarian assistance either due to exploitation, pre-existing discrimination, and stigma or due to a lack of adequate consideration”.<sup>33</sup>

These dynamics inevitably impact disability inclusion: the needs-based approach reinforces the welfare paradigm, which is already a significant challenge that persons with disabilities face, as well as structural marginalization. Within the UN-donor humanitarian frameworks, there are nevertheless a range of mechanisms and coordination fora in place that could both support inclusion and minimize exclusion and discrimination. Somalia’s Humanitarian Country Team (HCT) is headed by the UN humanitarian coordinator, with the UN Office for the Coordination of Humanitarian Affairs (OCHA) serving as the Secretariat. Through their coordination function, the role of HCTs is to provide strategic guidance and oversight of humanitarian action in a given country.<sup>34</sup> The Somalia HCT comprises UN agencies, donors, the Somali NGO Consortium<sup>35</sup> and a limited number of non-governmental organizations (NGOs), the latter being elected on a rotational basis.

HCTs are supported by the Inter-Cluster Coordination Group (ICCG). The ICCG provides coherence and plays a coordination role across the relevant sectoral areas, referred to as “clusters”, such as shelter, water and sanitation, protection, food security and nutrition.<sup>36</sup> Disability cuts across all of these clusters, with the level of priority given to the needs of persons with disabilities being particularly influenced by how and what information and evidence are gathered and analyzed.

## Claiming participation through membership

OPDs could potentially be represented on the Somalia HCT, either through the Somali NGO Consortium or as one of the rotating NGOs. With respect to the

31 A. Medinilla, L. Tadesse Shiferaw and P. Veron, above note 28, p. 9.

32 UN Accountability Project – Somalia, “Neither Inevitable nor Accidental: The Impact of Marginalisation in Somalia”, in Michael Keating and Matt Waldman (eds), *War and Peace in Somalia: National Grievances, Local Conflict and Al-Shabaab*, Hurst, London, 2018, p. 41.

33 OCHA, *Humanitarian Response Plan Somalia: Humanitarian Programme Cycle 2022*, December 2021, p. 24, available at: [https://reliefweb.int/sites/reliefweb.int/files/resources/2022\\_Somalia\\_HRP.pdf](https://reliefweb.int/sites/reliefweb.int/files/resources/2022_Somalia_HRP.pdf).

34 Humanitarian Library, “Guidance for Humanitarian Country Teams”, available at: [www.humanitarianlibrary.org/resource/guidance-humanitarian-country-teams-0](http://www.humanitarianlibrary.org/resource/guidance-humanitarian-country-teams-0).

35 See the Somali NGO Consortium website, available at: [www.somaliangoconsortium.org/](http://www.somaliangoconsortium.org/).

36 OCHA Services, Humanitarian Response, “Inter-Cluster Coordination Group (ICCG) Terms of Reference”, available at: [www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/iccg\\_tor\\_23mar2016.pdf](http://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/iccg_tor_23mar2016.pdf).

latter, the Somalia HCT's membership structure is defined by terms of reference which, for NGOs, require an established operational presence and programming as well as demonstrated commitment to participation in humanitarian coordination. These terms of reference are challenging for OPDs, which tend to be staffed by volunteers and do not have financial and organizational stability, sophisticated systems for proposal writing, reporting and accountability, or broad-ranging delivery mechanisms. In addition, because persons with disabilities have historically been viewed as beneficiaries of charity, there is an added power dynamic when trying to integrate themselves into mainstream NGO networks. For example, it is telling that a powerfully written March 2022 open letter from fifty NGO actors appealing to donors to fund the drought emergency response does not include OPDs, although some of the included organizations may work on disability.<sup>37</sup> To help remedy this, the Somalia HCT's terms of reference could be amended to ensure that the voices of OPDs are enabled, either through the Somalia NGO Consortium or as a standing agenda item on a monthly or similar basis. This approach would be in line with the HCT's strategic nature and also with the Grand Bargain commitment to localization.<sup>38</sup> Localization was considered a priority at the World Humanitarian Summit and refers to the call for humanitarian actors to be more inclusive of local actors in all phases of humanitarian action. The localization agenda also commits the humanitarian system to diversity and has explicitly acknowledged that "persons with disabilities and OPDs have tended to be sidelined within humanitarian coordination and decision-making platforms, reinforcing underlying inequalities that obstruct access to humanitarian services".<sup>39</sup>

Donor representation on the HCT also provides an opportunity to advocate for better disability inclusion in its priority setting and funding criteria.<sup>40</sup> Inspiration could be drawn from the UN–Foreign, Commonwealth and Development Office (FCDO) performance review of the humanitarian system, a commitment from the

37 "Joint Statement to the Donor Community: NGOs Call upon Donors to Urgently Fund Somalia Drought Crisis", 1 February 2022, available at: <https://reliefweb.int/report/somalia/joint-statement-donor-community-ngos-call-upon-donors-urgently-fund-somalia-drought>.

38 The Grand Bargain is an agreement between certain large donors and humanitarian organizations with the aim of improving the effectiveness and efficiency of humanitarian action. See Inter-Agency Standing Committee (IASC), Grand Bargain Workstream 2, commitment 3, available at: <https://interagencystandingcommittee.org/grand-bargain> (committing to "[s]upport and complement national coordination mechanisms where they exist and include national responders in international coordination mechanisms as appropriate and in keeping with humanitarian principles"). See also IASC, "Statement by Principals of the Inter-Agency Standing Committee (IASC) on Accountability to Affected People in Humanitarian Action", 14 April 2022, available at: <https://interagencystandingcommittee.org/accountability-and-inclusion/statement-principals-inter-agency-standing-committee-iasc-accountability-affected-people> (reaffirming commitment to diverse, locally led coordination platforms and local leadership).

39 IASC, *IASC Guidance on Strengthening Participation, Representation and Leadership of Local and National Actors in IASC Humanitarian Coordination Mechanisms*, July 2021, available at: <https://interagencystandingcommittee.org/operational-response/iasc-guidance-strengthening-participation-representation-and-leadership-local-and-national-actors>.

40 Article 32 of the UNCRPD, above note 15, reflects a comprehensive approach to international cooperation, including financial cooperation, cooperation in research and access to scientific and technical knowledge, capacity-building and training programmes, exchange of information and access to assistive technologies, etc.

Grand Bargain. Core funding support to seven UN humanitarian agencies was assessed on a set of requirements to improve effectiveness, coherence and collaboration in individual and collective humanitarian performance, referred to as “payment by results for agency budgets”. This incentive-driven approach means that Humanitarian Needs Overviews and Humanitarian Response Plans have to demonstrate that a certain “percentage” of the Response Plan is disability-inclusive; in 2020 this percentage was 70%, and in 2021 it was 75%. This process was accompanied by annual lessons-learned exercises for specific countries, including Somalia.<sup>41</sup> The exercise encouraged dialogue, helped raise awareness and provided practical examples of how disability can be included in the humanitarian architecture.<sup>42</sup> The criteria used could be extrapolated and adapted to country contexts such as Somalia. This would also support the implementation of Article 32 of the UNCRPD, under which States Parties have to mainstream disability inclusion in their international cooperation, including development assistance. While Article 32 could be narrowly construed as applying only to development contexts, this would be inconsistent with the UNCRPD’s objective of promotion, protection and ensuring the full and equal enjoyment of rights by all persons with disabilities.<sup>43</sup> In addition, the protracted nature of many humanitarian crises means that development elements are intrinsic to the responses to those crises – for example, water management. In this regard, various aspects of disability inclusion, whether in an emergency setting or not, require development interventions, such as assistive technologies, which are rarely factored into a humanitarian response. Given this, the Article 32 commitment should also be factored into States Parties’ humanitarian portfolios and should be read in conjunction with Article 11<sup>44</sup> and Article 31, addressing data and statistics. In addition, the Organisation for Economic Cooperation and Development (OECD) Development Assistance Committee’s “policy marker on the inclusion and empowerment of persons with disabilities” is a useful reference, providing guidance to relevant countries.<sup>45</sup>

## Making the invisible visible – prioritization

It is well documented that the lack of high-quality and comprehensive data available regarding persons with disabilities inhibits effective planning, budgeting and

41 Six focus areas were examined in the selected countries: use of technical guidance, participation, data, country team dynamics, leadership, and monitoring.

42 UNGA Res. 48/96, *UN Standard Rules on the Equalization of Opportunities for Persons with Disabilities*, UN Doc. A/RES/48/96, 14 March 1996, Rule 1, available at: [www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html](http://www.un.org/development/desa/disabilities/standard-rules-on-the-equalization-of-opportunities-for-persons-with-disabilities.html) (the importance of awareness-raising is reflected in the first standard rule, as persons with disabilities considered that attitudinal barriers are one of the most significant barriers to inclusion).

43 UNCRPD, above note 15, Art. 1.

44 Article 11 of the UNCRPD, above note 15, obliges States Parties to ensure the protection and safety of persons with disabilities in situations of risk, such as situations resulting from armed conflicts, humanitarian emergencies or natural disasters.

45 OECD, Development Assistance Committee, *The OECD-DAC Policy Marker on the Inclusion and Empowerment of Persons with Disabilities: Handbook for Data Reporters and Users*, 10 December 2020, available at: [https://one.oecd.org/document/DCD/DAC/STAT\(2020\)48/en/pdf](https://one.oecd.org/document/DCD/DAC/STAT(2020)48/en/pdf).

programme implementation<sup>46</sup> – or more simply put, “[i]f people with disabilities remain invisible in data, they remain unaccounted for”.<sup>47</sup> As humanitarian response is determined by needs,<sup>48</sup> it is essential that persons with disabilities are factored into that data collection and analysis. Efforts are under way to support this change, including through the Inter-Agency Standing Committee (IASC) *Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action* (Disability Inclusion Guidelines)<sup>49</sup> and monitoring.

In addition, the Accountability to Affected Populations initiative, which seeks to move from the notion of passive beneficiary of aid to someone who has agency, has a range of decision-making structures and processes that support community feedback, such as camp committees, disaster and risk coordination mechanisms, and hotlines.<sup>50</sup> The guiding principle is that consultation is not sufficient as it does not necessarily change an outcome; rather, a feedback loop system needs to be in place to ensure accountability. Given the power dynamics within communities, which are accordingly mirrored in community-based mechanisms, there is a need to invest in inclusion of persons with disabilities in these mechanisms, including through ensuring that they are accessible. This will support voices being better heard and ideally have a knock-on effect in addressing the relative invisibility in data collection and analysis exercises. Otherwise, crucial decisions will be made with what has been described as an ableist paradigm, meaning that persons with disabilities are excluded because there is a societal assumption that they have “less value than others” or because they are more broadly seen as beneficiaries who need care and are without agency.<sup>51</sup>

At the cluster level, disability tends to be housed under the HCT’s Protection Cluster, which historically happens to be the most underfunded.<sup>52</sup>

46 Ola Abualghaib, Nora Groce, Natalie Simeu, Mark T. Carew and Daniel Mont, “Making Visible the Invisible: Why Disability-Disaggregated Data is Vital to ‘Leave No-One Behind’”, *Sustainability*, Vol. 11, No. 11, 2019, available at: <https://doi.org/10.3390/su11113091>.

47 *Ibid.*, p. 3096.

48 The calculation of “people in need” in humanitarian contexts is challenging. The overall guiding principle is need, with some exceptions based on status. As such, there is no automatic assumption that persons with disabilities have need of humanitarian assistance in a humanitarian setting. Need is accordingly subject to an assessment process generally conducted at scale. See IASC Information Management Working Group, *Humanitarian Population Figures*, April 2016, available at: [www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/humanitarianprofilesupportguidance\\_final\\_may2016.pdf](http://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/documents/files/humanitarianprofilesupportguidance_final_may2016.pdf).

49 See Charter on Inclusion of Persons with Disabilities in Humanitarian Action, 2016, available at: <http://humanitariananddisabilitycharter.org>; IASC, *Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action*, 2019, available at: <https://interagencystandingcommittee.org/iasc-task-team-inclusion-persons-disabilities-humanitarian-action/documents/iasc-guidelines>.

50 See IASC, “Statement by Principals”, above note 38.

51 Catalina Devandas-Aguilar, *Report of the Special Rapporteur of the Human Rights Council on the Rights of Persons with Disabilities*, UN Doc. A/71/314, 9 August 2016, para. 31, available at: <https://daccess-ods.un.org/tmp/895524.546504021.html>.

52 Norwegian Refugee Council and Global Protection Cluster, *Breaking the Glass Ceiling: A Smarter Approach to Protection Financing*, November 2020, p. 6, available at: [www.globalprotectioncluster.org/wp-content/uploads/Breaking-the-glass-ceiling-A-smarter-approach-to-protection-financing-report-FINAL.pdf](http://www.globalprotectioncluster.org/wp-content/uploads/Breaking-the-glass-ceiling-A-smarter-approach-to-protection-financing-report-FINAL.pdf) (finding that the protection sector remains significantly underfunded in consolidated appeals relative to most other clusters and recommending, *inter alia*, that a fixed percentage of organizational funding goes to protection activities).

Somalia follows this trend, and since the Somalia HCT's adoption of the Centrality of Protection Strategy in 2017,<sup>53</sup> one of the three consistent strategic objectives has been addressing exclusion.<sup>54</sup> The Somalia HCT has gone further with a push on mainstreaming across all clusters, supported initially by an OCHA disability inclusion adviser.<sup>55</sup> Given how critical data are, clusters were trained on the IASC Disability Inclusion Guidelines, data issues and overall disability inclusion principles, which resulted in strengthened Humanitarian Needs Overviews and Humanitarian Response Plans. The then disability inclusion adviser recommended a roadmap comprising key areas of intervention, many of which have been taken up.<sup>56</sup> For example, in 2021, using the Washington Group Questions Short Set (WGQ-SS) as a basis,<sup>57</sup> the *Cluster Guidelines for Gathering Data on Disability* were adopted.<sup>58</sup> This means that the thematic clusters now have a tool that helps them to integrate disability into data collection and reporting modalities, many of which become public. For 2022, the Somalia HCT has also volunteered to be part of a self-assessment pilot on disability inclusion in Humanitarian Needs Overviews and Humanitarian Response Plans as a way to galvanize thinking and increase understanding.

Nevertheless, application of the WGQ-SS is not without complications and experience suggests that its use is seen as not viable or too time-consuming in emergency responses. This naturally results in limited information being available about the needs of persons with disabilities, creating a risk that they will be left behind. As such, strong leadership is vital to ensure that disability inclusion is taken seriously, not only in the HCTs but also in individual UN agencies and NGO partners.

Specific considerations should be placed on how assessments are conducted, including the training of enumerators and who those enumerators are, as well as the basic operating assumption that most data are collected at the household level.<sup>59</sup> For example, if we take the food security sector, planning and

53 The IASC principals' Centrality of Protection Statement confers clear responsibility on humanitarian coordinators, HCTs and cluster leads to ensure that protection is central to humanitarian action. See IASC, "The Centrality of Protection in Humanitarian Action: Statement by the IASC Principals", 17 December 2013, available at: [www.humanitarianresponse.info/en/topics/transformative-agenda/document/centrality-protection-humanitarian-action-statement-inter](http://www.humanitarianresponse.info/en/topics/transformative-agenda/document/centrality-protection-humanitarian-action-statement-inter).

54 Somalia HCT, "Humanitarian Country Team Centrality of Protection Strategy 2022–2023", available at: <https://reliefweb.int/report/somalia/somalia-humanitarian-country-team-centrality-protection-strategy-2022-23>.

55 The disability adviser served from April 2020 to March 2021, via standby partner Red R Australia, funded by Australia Assists.

56 On file with author.

57 The Washington Group Questions were developed by the UN Statistical Commission in collaboration with member States. The Short Set focuses on six core domains of functioning: seeing, hearing, walking, cognition, communication, and self-care. Respondents rate their functional difficulty on a four-point scale, from "no difficulty" to "cannot do at all".

58 On file with author.

59 SIDA, above note 11, p. 1 (stating that "[p]ersons with disabilities and elderly have great difficulty in accessing humanitarian aid. Persons with disabilities remain excluded from the most essential services in emergencies and are left behind in refugee camps. There are however efforts by the international community to do something about this in the various clusters").

response is driven through large-scale needs assessments or surveys.<sup>60</sup> Ideally, this is accompanied by qualitative tools such as community consultations which allow greater understanding to inform targeting decisions, prioritization and response. These assessments are the primary entry point for persons with disabilities to be brought into the humanitarian orbit. As such, certain considerations need to be kept in mind. First, community consultations are influenced by power dynamics, which are often more marked in conflict settings where access to populations is challenging. Persons with disabilities generally sit outside these power structures, and Somalia is no exception. Second, engagement is often remote; for example, assessments may be conducted over the phone, which excludes certain disabilities, usually those already more marginalized within the disability community, such as deaf people and persons with intellectual disabilities. To concretely help make the invisible visible, consultative and feedback processes should be designed to be accessible, with specific need considerations in mind – for example, ensuring that OPDs are brought into the design of such processes rather than relying on the broader community to identify who may be disabled, and training enumerators, community committees<sup>61</sup> and monitors on accessible communication techniques. Humanitarian actors should also consider crafting solutions for long-standing and deep-rooted social and cultural biases and power imbalances. This could be done by moving beyond indicators such as age and gender, to factoring in marginalization as a ground in vulnerability assessments.<sup>62</sup>

## The development continuum

While these efforts can ensure better visibility of persons with disabilities in protracted humanitarian and conflict settings, this does not automatically translate into their full participation in a development context. It has been acknowledged globally that there is a need to shift the balance in crisis settings towards development for there to be sustainable progress. This need is more patent in protracted settings where humanitarian actors have expanded their remit. As has been noted elsewhere, this puts a strain on humanitarian funding

60 The Integrated Food Security Phase Classification (IPC) determines the severity and magnitude of acute and chronic food insecurity, as well as acute malnutrition in a country. The aim is to arrive at a consensus-based figure of the level of food insecurity in a geographic area. See IPC, “IPC Acute Food Insecurity Classification”, available at: [www.ipcinfo.org/ipcinfo-website/ipc-overview-and-classification-system/ipc-acute-food-insecurity-classification/en/](http://www.ipcinfo.org/ipcinfo-website/ipc-overview-and-classification-system/ipc-acute-food-insecurity-classification/en/).

61 See e.g. Trinity College Dublin and World Food Programme, *Inclusive Accountability to Affected Populations: Mainstreaming Accessible Communication for Vulnerability-Based Targeting in Mozambique*, 2022, available at: [www.tcd.ie/slscs/research/assets/images/AccessibleMozambique.pdf](http://www.tcd.ie/slscs/research/assets/images/AccessibleMozambique.pdf). This paper discusses a pilot on inclusive community engagement which conducted messaging on assistance by using supported communication formats for people with communication disabilities, who are generally the most marginalized and excluded. The paper concludes that “[b]y prioritizing inclusion as a starting point, rather than an add-on, the result was increased access for all”.

62 UN Accountability Project – Somalia, above note 32, p. 43.

and creates “a mismatch between humanitarian mandates and coordination structures and the long-term strategies needed to respond to protracted crises”.<sup>63</sup>

The UN system has tried to address this through the concept of the humanitarian–development nexus, or, as in the case of Somalia, the humanitarian–development–peace triple nexus.<sup>64</sup> Given Somalia’s dependence on humanitarian assistance, the nexus approach has been welcomed and “is generally seen to be a critical condition for maintaining what has been achieved in the past few years”.<sup>65</sup> The UN’s efforts are also dependent on those entities funding the respective areas, which remains a challenge as governments generally divide development cooperation and humanitarian assistance portfolios, resulting in different management and accountability structures. The gap in coherence in Somalia – or as one external review on Somalia put it, the “siloes funding windows” in the country<sup>66</sup> – has led to development partners being called on to “consider reorganising management structures, strategy and planning processes, and allocation decisions around regional, country or subnational geographic areas – rather than humanitarian, development and political functions”.<sup>67</sup> One external review noted that “[t]here is little in the way of a ‘nexus’ on the ground in Somalia” and found that the UN and other partners were not “ready to bridge the gap between their sectoral specialisations”.<sup>68</sup> The deep structural changes necessary in Somalia were exposed during the COVID-19 pandemic when humanitarian actors provided the bulk of health services in the country due to a weak public health system.<sup>69</sup>

The UN’s development architecture in Somalia is built around the UN Sustainable Development Cooperation Framework (UNSDCF). The UNSDCF is designed to support the government’s development priorities, one of which is to strengthen the interface between humanitarian and development planning.<sup>70</sup> Conversely, the Somalia HCT’s terms of reference recognize the need to support the humanitarian–development–peace nexus and to coordinate where possible with development platforms.<sup>71</sup> This mutual recognition provides leverage for an issue such as disability inclusion to be a thematic focus across the humanitarian–development continuum, keeping in mind the normative guidance as expressed

63 C. Bennett and M. Foley, above note 30, p. 35.

64 A. Medinilla, L. Tadesse Shiferaw and P. Veron, above note 28, p. v (noting that “the ‘triple nexus’ between humanitarian aid, development and peacebuilding has become a commonly used term, especially in the context of the UN reform agenda and the ‘New Way of Working’”).

65 *Ibid.*, p. i.

66 *Ibid.*, p. iv.

67 S. Dalrymple and A. Thomas, above note 28, p. 8. It was also noted that the core issue is that development and humanitarian actors have different planning cycles for responding to their respective mandates. More specifically, development cooperation actors tend to plan on the basis of five- to seven-year strategies, often with a more decentralized decision-making structure, whereas humanitarian donors plan on the basis of much shorter time frames.

68 A. Medinilla, L. Tadesse Shiferaw and P. Veron, above note 28, p. vi.

69 S. Dalrymple and A. Thomas, above note 28, p. 38.

70 Somalia National Development Plan 2020–2024, available at: <https://andp.unescwa.org/plans/1245>.

71 Terms of Reference for Somalia Humanitarian Country Team, February 2022, paras 2.3, 3.2.8. On file with author.

by the Special Rapporteur on the Rights of Persons with Disabilities. She has emphasized that “[i]nclusive development cannot be effectively achieved in the absence of a human rights framework” and has called on States to “[e]nsure a human-rights based approach in the design, implementation and evaluation of all policies and programmes”.<sup>72</sup> This emphasis is highly relevant in the Somali context, where human rights, gender and inclusion are mainstreamed in both the government’s National Development Plan and the UNSDCF, the latter aligning with the government’s priorities. This necessarily means that issues such as disability rights and inclusion are, in principle, everywhere, but also risk being nowhere. As such, operationalization needs particular attention, and the minimum preconditions for inclusion, such as accessibility, support services and assistive devices, need to be in place.<sup>73</sup> The UN Disability Inclusion Strategy (UNDIS), issued by the UN Secretary-General in 2019, can also play an important role in this regard. The UNDIS places a heightened obligation on UN entities to demonstrate disability inclusion across the board, from organizational change and accessibility through to programming and projects.<sup>74</sup>

The triple nexus – that is, the humanitarian–development–peace nexus – should, in principle, enable disability inclusion to be taken one step further. In other words, to arrive at sustainable peace, broad-based participation is vital, including through processes that support reconciliation, and State-building. The next section explores the concept of participation and what considerations need to be taken into account in Somalia for persons with disabilities to claim it.

## Claiming participation

Ensuring disability inclusion is heavily dependent on how persons with disabilities and their representative organizations are enabled to participate.<sup>75</sup> Terms such as “engagement”, “consultation” and “participation” are used interchangeably in the context of disability, but all seek to respond to the systematic exclusion of persons with disabilities from decision-making processes that affect them. A research study commissioned by the European Union, entitled *The Unsteady Path*, unpacked these concepts, noting that “opening or creating participation space does not equate [to] meaningful participation, let alone effective changes

72 C. Devandas-Aguilar, above note 51, para. 78(b).

73 Alexandre Cote, *The Unsteady Path towards Meaningful Participation of Organisations of Persons with Disabilities in the Implementation of the CRPD and SDGs. A Pilot Study by Bridging the Gap*, 2020, p. 21, available at: <https://bridgingthegap-project.eu/wp-content/uploads/The-unsteady-path.-A-pilot-study-by-BtG.pdf>.

74 UNDIS, indicator 11, available at: [www.un.org/en/content/disabilitystrategy/](http://www.un.org/en/content/disabilitystrategy/).

75 The UNCRPD, above note 15, considers participation as fundamental to the enjoyment of all rights, framing it as general obligation 4(3), as separate rights (Articles 29 and 30), and in the overall monitoring of the Convention (Article 33(3)). See also A. Cote, above note 73, p. 5 (noting that the “emphasis on participation of persons with disabilities has been a response to their systematic exclusion from consultation and decision-making mechanisms related to design, planning and monitoring of policies, programs and services that affect their lives and their communities”).

for concerned population[s]”.<sup>76</sup> The research offers an analytical framework that is useful for the Somalia context. It warns that “participation can also be used to legitimize policies and processes that preserve [the] status quo or perpetuate inequalities”.<sup>77</sup> The framework looks at three elements: first, the State’s role in facilitating participation; second, the disability movement’s engagement; and third, the role and influence of international cooperation actors and service providers in the relationship between the State and the disability movement.<sup>78</sup> The ideal outcome of this set of relationships is that the State will be able to depend on a strong disability movement, which is in turn dependent on an engaged State that dedicates political space and resources to that movement. The capacity of both the State and the disability movement should be supported by international cooperation actors, who can also facilitate dialogue between them.<sup>79</sup>

Conflict settings add another layer of complexity to State-building, development and reconciliation initiatives, particularly with respect to who gets to participate in those processes. Or otherwise stated, conflicts absorb political energy, and in the struggle for political consensus, many issues end up being left off the table.

Somalia’s State-building process is anchored in a number of initiatives, including stabilization, reconciliation and constitutional review, all seeking to consolidate the State-building agenda. These initiatives already bring together two actors – that is, the State and the international community, and to some extent domestic civil society. Opening this space to the disability movement would help ensure its meaningful engagement in those critical processes and materialize a mutually reinforcing relationship between the State, persons with disabilities and international cooperation actors. Such inclusion would also help tackle societal stereotypes which can be partially summed up by the words of one Somali OPD representative, who stated: “persons with disabilities in Somalia are often not valued by society – they are frequently asked by their family, ‘what do you know?’”.<sup>80</sup> This level of stigmatization is of course a challenging starting point from which to claim participation. As part of its effort to address these challenges, the Somali government has acknowledged the necessity of moving towards the inclusion of persons with disabilities, including through the establishment of the NDA.

## Coalescing around Somalia’s National Disability Agency

The National Disability Agency was established in 2018, but officially launched by its five commissioners in 2021. It is a federal agency responsible for the design, development and implementation of the Somali government’s plan for persons

76 A. Cote, above note 73, p. 15. The project identified eleven “different stylized forms of interaction which may or may not be qualified as participation”.

77 *Ibid.*, p. 7.

78 *Ibid.*, p. 20.

79 *Ibid.*, p. 44.

80 UNSOM HRP and UN Human Rights, above note 22.

with disabilities, and it leads on legal reform in relation to disability.<sup>81</sup> A key objective of the NDA's Establishment Act was also to ensure that Somalis with disabilities have a body to represent them and advocate for their rights.<sup>82</sup>

After the launch, the NDA immediately started its work with three main objectives: first, to raise awareness about the Agency and what it is mandated to do; second, to start its engagement with OPDs, with the aim of finding ways to help them have a voice and engage international community interest; and third, to influence the government system, planning and budget allocation. The latter is critical from a purely practical point of view as the NDA's financial support is limited to stipends to the commissioners, who are currently working out of homes or hotels. The Ministry of Women and Human Rights Development, which is already trying to find space for its own staff, has provided a small office, but the bathrooms are inaccessible, which means that it remains largely unused.<sup>83</sup>

The NDA motivated a group of UN entities and the Camp Coordination and Camp Management Cluster and Protection Cluster to support it. A range of ideas were discussed, and it was eventually agreed that a country-wide survey which aimed to understand the perspectives and priorities of persons with disabilities would be the best entry point. The rationale was that the overarching goal was for the NDA to create a relationship of confidence and trust with OPDs that would evolve into a structured mechanism for consultation and joint advocacy. The launching of the survey would provide a platform for the NDA to discuss its mandate and engage with OPDs at the local level, including support in identifying community members and enumerators. In addition, it was agreed that the NDA was not in a position to undertake a typical needs assessment as it does not have the capacity to meet such needs or expectations; rather, by focusing on perspectives and priorities, the survey would be a tool to bring persons with disabilities and their representative organizations into a State–citizen dialogue. The survey's development was initially informed by a typical humanitarian needs assessment tool for internally displaced people with disabilities, based on the WGQ-SS and also including the WG-UNICEF Child Functioning Module.<sup>84</sup> The process of negotiating additional questions and removing others was fascinating, involving the NDA, OPDs, UN partners, clusters, the National Bureau of Statistics, and Trinity College Dublin.<sup>85</sup> It was recognized early on that there needed to be a development dimension that should be grounded in human rights, particularly in relation to claiming participation and accountability. The methodology was also crafted in such a way as to foster greater cross-sectional

81 Federal Government of Somalia, National Disability Agency Establishment Act, 2018.

82 *Ibid.*, Art. 5.

83 Site visit by author, 8 December 2021, and subsequent interview with the NDA.

84 See UNICEF, "Module on Child Functioning: Questionnaires", available at: <https://data.unicef.org/resources/module-child-functioning/>.

85 Trinity College Dublin has been providing support to UN Human Rights in Somalia since 2021 on disability inclusion issues, particularly in relation to quantitative and qualitative data collection and analysis.

representation, increased participation by women with disabilities, increased inclusion of children with disabilities, and broader geographical coverage.

The survey was piloted in one regional capital in early 2022, and while it is too early to discuss the overall findings, the need to support participation claims clearly came across through the survey, most notably in responses to questions about representation of persons with disabilities. For example, 90% of persons with disabilities who took the survey stated that they had not been involved in community decision-making processes. Some 84% stated that they did not think that the rights of persons with disabilities are considered in political discussions. Interestingly, a lower number of persons with disabilities, 57.8%, felt that they were treated negatively or differently due to their disability status. Based on the responses, the next stage is to take a smaller subset of survey participants, both in key informant and focus group formats, and follow up with qualitative questions addressing participation.

Applying the analytical framework for participation discussed above, the NDA is moving steadily towards a situation where it, as a State entity, and OPDs are contributing to and collaborating on carving out a participation space. The following section outlines some recommendations on how that can be reinforced, especially at this nascent stage.

## Conclusion and recommendations

In its current form, the typical humanitarian architecture, even where there is political will, has a limited ability to address the exclusion of people with disabilities and, more broadly, the rights of persons with disabilities. This is because it operates on a needs-based approach that serves beneficiaries as opposed to rights-holders – hence, it can inadvertently reinforce an already stigmatizing charity or welfare approach to persons with disabilities.<sup>86</sup> Furthermore, from the perspective of representation or having a role in the delivery of structured humanitarian action, few OPDs have the governance systems in place that could provide the breadth of services that are required to compete in a call for proposals for the different sectoral areas involved, such as water and sanitation, food security or shelter. Similarly, while the Accountability to Affected Populations framework has improved, it depends heavily on engagement with existing power structures and the set of identified beneficiaries. As persons with disabilities often sit outside these structures or are not reached in large-scale needs assessments, their voices are not always being captured. If this

86 C. Devandas-Aguilar, above note 51, para. 11 (stating that “policy efforts should move away from the charitable and medical approaches towards a human rights-based approach to disability, where persons with disabilities are considered as rights holders, rather than mere receivers of protection, rehabilitation and/or welfare”). See also Peter Uvin, *Human Rights and Development*, Kumarian Press, Bloomfield, CT, 2004, p. 54 (recalling Paul Farmer’s use of the term “pragmatic solidarity”, which Uvin criticizes as depending too often “on the continued presence of foreigners and foreign money, and it sometimes unintentionally ends up disempowering local dynamics of social change”).

work is also taking place in a conflict setting, challenges are exacerbated due to the natural division of who is negotiating peace and who is awaiting those peace dividends. Nevertheless, as the Somalia example demonstrates, HCTs can do a lot with leadership, a willingness to leave agency branding behind, and an active committed partner such as the NDA. However, with system dependency on annualized funding, the Somalia HCT will not be able to fill the NDA's resource void, which needs more sustainable options.

On another note, as is evident from the nature of protracted humanitarian settings, humanitarian action does not operate in a hermetically sealed bubble; rather, it moves in and out of different spaces, particularly in a conflict setting.<sup>87</sup> In addition, frameworks for a different approach to action, such as the triple nexus, can also be harnessed. The following recommendations seek to identify some potential areas for further exploration.

## Frameworks

- Humanitarian needs assessments, response plans and the like should pay more attention to indicators that define disability inclusion as an outcome, rather than simply being focused on outputs of the number of persons with disabilities reached.<sup>88</sup>
- As has been stated elsewhere, the WGQ-SS was “not designed to be used in isolation”<sup>89</sup> and should be included in all relevant surveys, assessments and registration documentation to support disaggregation on the basis of disability across humanitarian, development and peace-related spheres, including political participation. Where possible, quantitative assessments should be supported by qualitative data exercises to strengthen understanding of marginalization dynamics.
- In this regard, using the WGQ-SS as a starting point, disability inclusion is an ideal thematic to test the potential value of the triple nexus. As described above, the humanitarian–development nexus is relatively straightforward, and the third element of peace can be partially addressed by supporting “claiming participation” initiatives; for example, as Somalia moves to universal suffrage, the government should ensure that the NDA has a place at the National Independent Electoral Commission's first national stakeholders' conference.<sup>90</sup> The NDA would have the responsibility of engaging and consulting effectively across the entire disability constituency – age, gender, type of disability and location – thereby transcending any historical identity claims.

87 A. Medinilla, L. Tadesse Shiferaw and P. Veron, above note 28, p. 3 (noting that “[f]or target communities, the distinction between humanitarian, development and peace and security efforts is artificial”).

88 World Food Programme, “WFP Global Protection and Accountability Policy”, 11 November 2020, available at: [https://executiveboard.wfp.org/document\\_download/WFP-0000119393](https://executiveboard.wfp.org/document_download/WFP-0000119393).

89 O. Abualghaib *et al.*, above note 46, p. 3094.

90 S. Dalrymple and A. Thomas, above note 28, p. 38 (stating that the government in Somalia needs to take on a stronger decision-making role in crisis response in order to reduce dependency on humanitarian aid, but noting that “this remains challenging in the absence of a genuinely inclusive electoral process”).

- Strengthening disability inclusion will also depend on the extent to which the individuals whose rights are affected are willing to exercise and use their rights. Thus, the humanitarian apparatus needs to guarantee access to the disability community and embed its participation in it. This could take the form of ensuring representation in the HCT or Inter-Cluster Coordination Group, donor accountability using the Article 32 framework on mainstreaming disability into international cooperation, and through effective Accountability to Affected Populations initiatives. Given historical marginalization, capacity-building elements should also be included in support to OPDs.
- States Parties' obligations under Article 32 could be better met through disability data disaggregation in humanitarian and development programming as well as drawing on initiatives similar to the UN-FCDO "payment by results" model.
- The UNCRPD Treaty Reporting Guidelines in relation to Article 11 could be strengthened to guide on the often "non-emergency nature" of humanitarian crises – that is, focusing on how disability inclusion can be addressed in protracted settings.

## Partnerships

- Support national entities such as Somalia's NDA; this will help humanitarian actors to strengthen relationships with OPDs and demystify OPD engagement, thereby transforming the relationship from one of beneficiaries to one of rights-holders who have agency.
- Leverage the UNDIS, which includes an indicator on disability inclusion in programmes and projects, and engage with the UNDIS Secretariat, which has an extensive network, including in peace operation settings.
- Link national entities, such as the NDA, to the academic community. The Trinity College Dublin experience demonstrates that such entities could benefit from the latest methodological approaches and analytical experience, as well as lessons learned from other countries that such academic institutions work in or on.
- Ensure that disability data collected is linked to the work of the National Bureau of Statistics or equivalent in order to start building an archive of information and data to inform planning, programming and budgeting. This would also help raise awareness within national statistics bureaux on disability issues and ideally inform policy direction and analytical approaches to support system change.