



Overview of Research Project: Assistive technology in humanitarian settings

> Gavin Wood and Golnaz Whittaker February 2022

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1. Children with disability

There are 240 million **children** with **disabilities**¹ in the world; half of them are out of school. Many are invisible, stigmatized, hidden by their families and abandoned by their governments. UNICEF and its partners believe that, regardless of ability, **all children** have a right to reach their full potential.

With estimates of persons with disabilities across the world projected to double² from 1 billion in 2021 to 2 billion by 2050, the lives of more children will only get worse unless we act to include those with disabilities.

Children with disabilities, especially in humanitarian settings, are among the poorest members of the population and one of the most marginalized and excluded groups in society. They face daily discrimination in the form of negative attitudes and through the lack of adequate policies and legislation. About half of all children who live with disabilities do not go to school and are effectively barred from realizing their full potential.

UNICEF has reinforced its Core Commitments to Children by including the Convention on the Rights of Persons with Disabilities (CRPD) as the third main international human rights instrument serving as its foundation – in addition to the CRC³ and CEDAW.⁴ In doing so, UNICEF further strengthens its commitment to provide:

- 1. Inclusive needs assessments, planning and monitoring the needs of children with disabilities and of their caregivers are identified and reflected in planning and monitoring.
- 2. Inclusive and safe access to information and services children with disabilities and their caregivers have safe access to humanitarian programmes.
- 3. Participation children with disabilities participate in the design of programmes and in the decisions that affect their lives.

2. Why assistive technology?

The CRPD was adopted in 2006 and makes clear that the need for assistive technology (AT) is paramount. AT includes assistive devices (e.g., wheelchairs, prosthetics, orthotics, etc.) but, critically, also includes the services and regulatory frameworks, policy instruments, infrastructure, and trained caregivers and technicians that make up the 'ecosystem' to enable assessment and provision and maintenance of assistive devices.

In a humanitarian crisis, accountable agencies for the humanitarian response – including national governments and UN agencies – have a duty to work together to comply with the requirements of the CRPD, including AT. With only an estimated 1 in 10 children with a need for assistive devices having access, UNICEF's Office of Research – Innocenti undertook a study to better understand the nature and drivers of AT access in humanitarian settings and to present the available evidence on how to fill any gaps.

¹ The Convention on the Rights of Persons with Disabilities states that: "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".

² World Health Organization estimate.

³ CRC: Convention on the Rights of the Child

⁴ CEDAW: Convention on the Elimination of All Forms of Discrimination Against Women.

3. The AT project

3.1. Overview

This document provides a synthesis of the various reports and papers resulting from UNICEF Office of Research Office Innocenti's project on assistive technology (AT) in humanitarian settings. The project was conducted in two phases:

- 1. A <u>thematic literature review</u> to summarize the academic evidence base from the past decade regarding the provision of AT in humanitarian settings, including the nature and scale of provision and barriers and facilitators of access and provision.
- 2. Case studies of countries affected by crisis to triangulate the findings of the literature review and fill identified knowledge gaps with real-world examples.

The case study settings chosen were <u>South Sudan</u> and <u>Afghanistan</u>, two countries experiencing protracted crises. Each has received significant humanitarian aid over a long period and therefore is expected to have had the opportunity to commence some level of AT provision. The two settings also have contrasting features (e.g., differing geographical challenges, demographics, policy environments and responses from the international community) which offer the opportunity to understand whether contextual factors have had an impact on AT provision.

As the global COVID-19 pandemic coincided with this research, a third case study examined the pandemic's impact in the <u>State of Palestine</u>, using a comparable methodology to that used in Afghanistan and South Sudan.

Both the thematic literature review and the case studies are summarized here to highlight the key findings as well as the policy and operational repercussions and recommendations. **Through ongoing engagement with country offices and the Programme Division NYHQ** (and, periodically, Supply Division) **there has already been an impact of this research on the work of UNICEF** ahead of finalized production of the reports.

4. Thematic literature review

An important factor in the scope of this research was to present **opportunities and recommendations over which UNICEF has control or influence in its work in humanitarian action**, and to present external barriers that must be accounted for. As such, we conducted a search for academic literature reporting on any type of AT provision where there was an international humanitarian response triggered by a crisis. We limited the search to literature published in English between January 2010 and June 2020. We identified over 70 articles that met the inclusion criteria, though we noted that most articles only briefly discussed AT in the wider context of emergency medical treatment provided in the immediate aftermath of crisis.

The findings of the literature review are summarized below and are also available as two papers: a full thematic literature review focusing on children and adolescents, and a second paper (published by the <u>RESNA journal</u>) looking at persons with disabilities, without the specific child focus.

Project impact to date

Through ongoing engagement with the Country Offices Programme Division NYHQ and, periodically, Supply Division, there is already an impact of this research on the work of UNICEF ahead of finalized production of the reports:

Country offices are using Innocenti's AT case study findings and working to incorporate them into their various planning and advocacy tools, including:

- Incorporating the findings into their annual situation analyses
- Taking recommendations into the next United Nations Development Assistance Framework
- Integrating with other research findings (for the State of Palestine) as part of the Common Country Analysis on Disability
- Supporting UNICEF in influencing new by-laws (for the State of Palestine) relating to the new Disability Law
- Continuing dialogue with UNICEF Office of Research (OOR) to produce additional derivative products as support to policy, advocacy and operations.

Programme Division is engaging with UNICEF OOR to co-develop and fund a global research agenda that is inclusive of the full disability agenda – research that can be accomplished by UNICEF OOR, but also by the whole UNICEF evidence community, and outside: the global academic community, organizations of persons with disabilities, the International Disability and Development Consortium members, and more.

4.1. Summary of the literature

Literature specific to the AT needs of children and adolescents in humanitarian settings is lacking. This is a problem because children and adolescents have different needs from adults and present distinct challenges for service providers. In particular, children have different functional requirements (to play and learn, for example) and growing bodies, which necessitate more regular replacement and (re)fitting of some types of assistive products. The literature review found few examples of systematic or coordinated AT provision in humanitarian settings: only 15 articles described rehabilitation services inclusive of a specific form of assistive product or service for persons with disabilities.

Caution must be taken in drawing conclusions about other low- and middle-income countries beyond those cases cited in the literature reviewed that draw significantly from studies in Nepal and Haiti including, to a lesser extent, Uganda, Ethiopia, Iraq, South Sudan, Chad, the Democratic Republic of Congo, Afghanistan; and post-earthquake Pakistan.

The literature suggests that AT provision is typically delivered by NGOs, at small scale, and is specialized to single types of impairment – with mobility impairments being the most represented provision. However, the literature criticized some NGO-led AT provision in crises. For example, **assistive products donated without considering their appropriateness to the context or user, and without providing the necessary fitting and maintenance services**, i.e., provided without the necessary supporting AT ecosystem.

Much of the academic literature focused on the AT needs of those who acquired an impairment as a direct result of a crisis. Consequently, those who lose or whose assistive products are damaged in a crisis and **those** with AT needs that were unmet prior to a crisis are typically overlooked.

The review of the literature identified several barriers to AT provision, many of which are interrelated. Those barriers are likely to drive the gap between AT need and provision in humanitarian settings, in terms of both quality and quantity.

4.2. Demand-side barriers

- Stigma towards persons with disabilities that prevents families from adequately supporting their children in accessing AT.
- Lack of awareness of available AT services and products.
- Lack of understanding by individuals of their rights to AT.
- Lack of awareness of the benefits of AT.
- Lack of access to facilities where AT is provided due to the cost (or danger) of travel and the cost of products, services and maintenance.

4.3. Supply-side barriers

- Poor-quality health infrastructure, including a lack of trained personnel, making it difficult for humanitarian actors to build AT sustainably into existing health systems.
- Crises, leading to further loss of infrastructure, further weakening the health systems on which AT services rely.
- Coordination structures established in crises rarely understand or make clear who is responsible for AT provision. The influx of humanitarian NGOs creates challenges for coordinating the provision of AT, leading to a risk that parallel systems are established outside national healthcare systems.
- Humanitarian actors rarely conduct adequate AT needs assessments, limiting the potential of actors to develop appropriate AT programmes or even identify the demand.
- AT is particularly costly compared with other humanitarian programme supplies, primarily because most are developed for high-income countries and have ongoing costs associated with their repair, maintenance and replacement.

5. Country case studies

The aim of the case studies was two-fold: to build evidence and fill gaps in knowledge identified through the literature review, and to provide a focused report with recommendations for case country offices to consider going forward.

Each case study describes what is known about AT needs, maps the AT providers and services available, and identifies the barriers and enablers of provision. They describe the landscape of AT provision in the humanitarian settings of <u>Afghanistan</u>, <u>South Sudan</u>, and the <u>State of Palestine</u>.⁵

As there was good evidence of the barriers to AT access for children with disabilities, a key objective of the case studies was to focus on explaining the (low) levels of AT provision. As such, the focus of our research was on providers rather than recipients of AT services, and therefore on the staff in agencies with a role in provision. We aimed to ensure representation from government, donors, multilateral organizations, international and local NGOs, and civil society.

⁵ Case studies included a review of the grey literature on assistive technology provision in addition to the afore-mentioned global literature review. Websites of key agencies with a role in the provision of humanitarian services were also searched and snowballing sampling methods were used to build the literature base. Only articles published in English (a limitation) between January 2010 and September 2020 were reviewed. Organizations that play a role in the provision of assistive technologies in each location were contacted for interview.

5.1. Case study findings (South Sudan and Afghanistan)

There are strong parallels in both countries despite the contextual differences. In both locations:

- Donors and multilaterals do not fund bilateral AT programming;
- International humanitarian actors provide minimal monitoring of the extent to which national health services (or other services and facilities) meet the needs of persons with disabilities;
- AT provision is almost exclusively based in difficult-to-access urban centers;
- Most of the AT devices provided are mainly for mobility, with few provided for visual, hearing, cognitive and communicative impairments;
- AT is not systematically provided; it is ad hoc and organized by NGOs, which provide devices and services with limited capacity;
- AT needs assessments are not being conducted in either setting, limiting the ability to develop programming that meets children's AT needs.

5.1.1. Afghanistan

Almost all AT provision in Afghanistan is led by a small number of NGOs, and most provide mobility devices. Most NGOs providing such devices do so through rehabilitation centers, which are almost all located in provincial capitals, making them difficult to access by the majority rural population. We found few examples of free-of-charge AT for visual, hearing, communicative or cognitive impairments. As a result, it is likely that most children with such impairments do not have access to the devices they need. Key barriers to access include high levels of stigma against children with disabilities, constraining demand, and a paucity of provision, particularly for populations who need it most.

The lack of AT provision is driven by a variety of interrelated factors. These include limited data on AT need; failure of the government and humanitarian agencies to prioritize the needs of children with disabilities; and low technical capacity by these responsible actors to initiate, maintain and expand quality AT services.

Full report: Whittaker, G., and Wood, G.A., 2021, <u>Barriers and Facilitators to Providing Assistive Technologies</u> to Children with Disabilities in Afghanistan, p. 57, UNICEF Office of Research – Innocenti, Florence, Italy, 2021.

5.1.2. South Sudan

Almost all AT provision in South Sudan is led by a small number of non-governmental organizations. Only five organizations were currently distributing assistive devices systematically. Most free-of-charge provision is of mobility devices, though that provision falls below the level needed. We found few examples of AT provided for visual, hearing, communicative or cognitive impairments beyond a single eye hospital, which cannot meet the needs of the whole population. It is likely that most children with such impairments do not have access to the devices they need. Key barriers to access include high levels of stigma against children with disabilities, which inhibits demand, and the lack of provision particularly for those living in remote and insecure locations.

Provision of AT in South Sudan is constrained by several factors. These include absence of data on the level and type of AT needs among the population affected by the crisis; failure of the government and humanitarian agencies to prioritize targeted support for children with disabilities; failure of the government to sign the Convention on the Rights of Persons with Disabilities or to develop any plans to provide services to children with disabilities; low technical capacity by responsible actors to initiate, maintain and expand quality AT services; and denial of humanitarian access by parties to the conflict.

Full report: Whittaker, G., and Wood, G.A., 2021, <u>Barriers and Facilitators to Providing Assistive Technologies to</u> <u>Children with Disabilities in South Sudan</u>, p. 55, UNICEF Office of Research – Innocenti, Florence, Italy, 2021.

5.2. Impact of COVID-19 on AT in the State of Palestine

Like most countries globally, restrictions imposed by the State of Palestine to curb the spread of COVID-19 consequently restricted access to many services, including the provision of rehabilitation and AT. Some planned and operational rehabilitation and AT-provision services had been paused or delayed. Beyond the closure or reduction of services due to their inaccessibility (as a result of mobility restrictions), the pandemic also had negative impacts on programming processes, for example in procuring assistive devices.

A key concern by some providers was the possible or actual diversion of organizational funds from rehabilitation services to the emergency pandemic response.

We found examples of rehabilitation programmes adapting positively to pandemic restrictions by identifying and taking forward remote-delivery approaches.

Full report: Whittaker, G., and Wood, G.A., 2021, <u>The Impact of the COVID-19 Pandemic on the Provision of Assistive Technologies to Children with Disabilities in the State of Palestine</u>, p. 23, UNICEF Office of Research – Innocenti, Florence, Italy, 2021.

6. Implications of project findings

There is consensus in the literature that effective AT provision systems be:

- Focused on the needs of AT users and adapt products to user needs;
- Supported by rights-based policies;
- Based on procurement systems that source affordable, contextually appropriate assistive products;
- Inclusive of systems for identifying, training and deploying personnel with the capacity to provide associated AT services, such as fitting and orientation;
- Built on the regular collection of AT-related data, including data on the needs and use of AT products.

Agencies with a role in AT provision should note three key findings from this project:

- 1. AT provision currently focuses on children who acquire an impairment as a direct result of the crisis and overlooks children who lose their AT in the crisis, or who had a pre-existing impairment and never had their AT needs met.
- 2. In cases where humanitarian agencies consider the needs of children with disabilities, this is mostly focused on making mainstream humanitarian facilities and services inclusive, while the specific needs of children with disabilities (such as AT) are overlooked.
- 3. Rehabilitation in humanitarian settings is likely to focus on mobility impairments at the expense of other impairments (though there is likely still a gap between mobility AT needs and provision).

Additionally, the barriers identified through this work represent a range of inter-connected issues that are perhaps best addressed holistically to improve the quality and scale of AT provision in humanitarian settings. Based on the finding of the literature review and the case studies, a central barrier is the failure of host governments and donors to prioritize AT provision in humanitarian settings, as evidenced by the lack of available funding and programming for AT interventions. Once a decision to prioritize AT provision is made, responsible agencies must make several policy and operational decisions, while considering of the limited evidence available of best practices for AT provision in crises.

6.1. Policy and operational choices

In any humanitarian setting, multiple organizations will be needed to provide AT and tackle barriers. Organizations include the host government, international donors, humanitarian cluster/sector coordinators (including UN agencies), NGOs and civil society. Following are examples of policy and operational choices to be made early in a humanitarian response:

- Sectoral approach: Whether AT is coordinated, procured, and distributed through a single sector's coordination mechanisms (e.g., via the health cluster) or cross-sectorally (e.g., via education, protection and health clusters together).
- Specialization: Whether implementers should be responsible for provision of all types of AT across a geographic area, or provision of AT for one or more type of impairments across multiple areas (i.e., having specialist or non-specialist implementers).
- **Distribution:** The most efficient and effective mechanism for delivery of different AT services (i.e., under what circumstances to use community, primary or tertiary healthcare levels for distribution).
- **Evidence:** The choice of tool to acquire data on AT needs rapidly (by geography, type of need, etc.).
- Manufacture and procurement: The extent to which implementers should establish local manufacture of assistive products.

6.2. Lessons from good practice

Following are examples in the academic and grey literature of success factors for the provision of AT in some settings:

- Including children with disabilities in preparedness planning;
- Partnering with local civil society organizations;
- Improving effective data gathering on the prevalence and needs of children with disabilities;
- Rehabilitating services into emergency medical teams, to enable early interventions and continued provision;
- Building the capacity of local personnel to strengthen a sustainable healthcare system;
- Coordinating humanitarian response structures around a clear, designated 'space' for rehabilitation and AT provision within the Inter-Agency Standing Committee Cluster system;
- Stockpiling and prepositioning assistive products;
- Building partnerships with existing community based rehabilitation (CBR) programmes including building national CBR capacity.

6.3. Project recommendations

This review is expected to prompt agencies to consider the lessons learned, as described in the reports, and to develop and implement humanitarian responses on the specific needs of all children with disabilities rather than focusing only on mainstreaming (as noted at the end of the overview on Page 1, this is already happening).

Response plans must not only focus on those injured in the acute phase of a crisis but should include those who have lost their AT as a consequence of the crisis, and on those who never had their AT needs met in the first place. The focus should be on all types of impairment and not only mobility.

To that end, agencies should adopt the lessons learned outlined above and focus on:

1. Effective coordination for the provision of AT, including:

- Developing a global AT coordination framework for humanitarian settings, detailing the responsibilities of different agencies under different models of coordination (including the Cluster system and Refugee Coordination Model);
- Adopting Inter-Agency Standing Committee standards for measuring AT needs and provision as routine;
- Embedding rehabilitation that is inclusive of AT provision within emergency medical teams.

2. Strengthening systems for AT provision, including:

- Commitment from donors and multilateral agencies to ringfence humanitarian and development funding for AT provision programmes;
- Working closely with government and national stakeholders to develop strengthened AT systems, including existing national community-based rehabilitation schemes;
- Ensuring monitoring and evaluation of all AT programming to build the evidence base;
- Humanitarian procurement teams should expand supply catalogues to include assistive products (e.g., the current APL26 from UNICEF and WHO).
- 3. Designing programmes for AT provision based on analysis of the barriers identified in this review, including:
 - The range of pre-existing barriers, the within-crises barriers that are external to the humanitarian response and especially, those internal barriers that are controllable, to an extent, by the humanitarian system. The political economy should be central to this analysis.
 - Programmes to provide AT alongside appropriate sensitization and awareness raising, in order to tackle stigma and build demand for AT.

6.3.1. Closing remarks on recommendations

Donors, governments, multilateral agencies (including UNICEF) and NGOs have a role to play in all these priority actions. In a pre-crisis setting there are opportunities for UNICEF to assess the national legislation to understand the status of policies and standards with respect to the UN Convention on the Rights of Persons with Disabilities. There are further opportunities to identify and work with active organizations of persons with disabilities and to understand actual and potential funding sources and flows to children with disability alongside potential ministries and technical committees that could provide the basis of a coordination function. That same mapping not only provides opportunities for strengthening coordination, but it may also identify barriers and solutions to overcome or mitigate limited AT access – and to services in general – for children with disabilities during a crisis.

An analysis of those enabling frameworks and the barriers discussed in the project's various reports, summarized above, provide the framework for system strengthening ahead of humanitarian crises. That is, identifying opportunities to build capacity through training of nationals in the various areas of AT provision, from manufacture and supply to rehabilitation services, maintenance and integration.

Additionally, bridging the development-to-humanitarian nexus using a humanitarian response strategy with the same understanding of the barriers and enablers, provides the greatest opportunities for building back better and for identifying co-leaders (line ministries, organizations of persons with disabilities, and other existing coordination groups) to take forward coordination of an inclusive response during and after an emergency.

6.3.2. Assistive technology research opportunities

- Data collection: There is very little data on the scale and nature of AT needs in humanitarian crises. This is partly the result of a lack of evidence on the most effective approaches for identifying AT needs in these settings. Evidence on best practice is urgently needed.
- Models of provision and procurement: There is little evidence of the impacts and outcomes of different approaches to coordination, procurement and distribution. This is likely because there have been very few coordinated approaches to AT provision in humanitarian settings.
- Tackling stigma and awareness: There is little evidence on best practice to improve awareness of and demand for AT among families of children with disabilities.
- Barriers and facilitators of donor investment: This project's case studies found that donor prioritization and investment in AT was a key barrier to provision. Understanding the factors that play into this failure to prioritize would be a valuable topic for further research.
- **Low-cost devices:** As cost is likely to be a key barrier to provision, there is a need to pilot and evaluate low-cost, low-tech AT programmes.

Opportunities for research

The current research on assistive technology has highlighted several key areas where research on AT is anticipated, but there remain bigger gaps on:

- Best practices of disability inclusion; the impact of disability data on programming
- Intersectionality of programming (age, gender, disability, etc.) in support of disability outcomes
- Programme costing models for inclusive programmes and services for children with disabilities; inclusive education for children with disabilities; etc.
- Violence against children with disabilities
- Online learning and digital technology for accessing education by children with disabilities
- The humanitarian-development nexus agenda
- Climate change

A global research agenda

There is an opportunity to establish a global agenda steered by inputs from within and outside of UNICEF, with donors, international non-governmental organizations, the global research community, children and youth with disabilities, UN Agencies, and organizations of persons with disabilities.

Research is key to understanding how to maximize opportunities for children living with disabilities. It exposes the barriers that prevent children from enjoying their rights.

Research can provide answers to overcome obstacles and support humanitarian action that can **put all children first**.

for every child, answers

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