

Applying the IASC Guidelines in the Syria humanitarian response:

How an investment by Humanity & Inclusion to support the humanitarian response to the Syria crisis has paid off

Summary

This case study looks at Humanity & Inclusion's deployment of an Inclusion Specialist beginning in late 2019 to support the mainstreaming of disability in the overall Syria response through technical support and capacity development activities. The purpose of the study was to draw out lessons learned from the experience of Humanity & Inclusion (HI) that could inform future deployments of technical experts on disability inclusion, as well as to make the case why this type of technical support is critical if the humanitarian system wants to make sustained progress with disability inclusion.

The study took place over several months in 2021 and involved the review of documentation and key informant interviews with twenty different stakeholders who were involved in different ways with the Inclusion Specialist's work. The study was not intended to be evaluative.

HI's Inclusion Specialist was based in Amman Jordan and provided support from there to the Humanitarian Country Team Coordinated Response, the Humanitarian Needs Assessment Program, the Humanitarian Liaison Group and Protection Cluster in Gaziantep Turkey, as well as to the Northeast Syria NGO Forum Coordinated Response. The position was established in the context of HI's on-going support to other organizations' efforts in inclusive coordination that had been already underway for five years. The Inclusion Specialist was also deployed at a moment when interest in disability inclusion in the Syria response was significant and growing due to the recent release of disaggregated data by the Humanitarian Needs Assessment Program, which had used the Washington Group short-set questions in a Syria-wide household survey the year before. As well, at about the same time as the beginning of the Inclusion Specialist's assignment, the IASC Guidelines on the inclusion of persons with disability in humanitarian action were formally launched globally.

HI's Inclusion Specialist worked on two levels simultaneously, promoting change at the level of the humanitarian system as well as providing direct support to operational actors through mechanisms such as the Inclusion Technical Working Group under the Protection Cluster in Turkey. The foundation for her engagement were the IASC guidelines whose four "must do" actions were developed into a Theory of Change for how operationalization of inclusion mechanisms in the humanitarian response could occur.

The Inclusion Specialist was given the freedom of a very broad mandate because the initial premise of the deployment – to support the Health Cluster, through its Trauma and Disability Working Group – proved infeasible. Instead, the Inclusion Specialist provided support to several different processes simultaneously: to the AAP/PSEA/Inclusion Working Group for the Northwest Syria response, the Inclusion Technical Working Group under the Protection Cluster in Turkey, the Humanitarian Needs Assessment Program, the OCHA team to support the Humanitarian Program Cycle processes and operation, as Gender Focal Point for the Northwest Syria WASH Cluster, the Northeast Syria NGO forum, and the Syria Cross-border Humanitarian Fund (SCHF).

Among the many contributions HI's Specialist made, the one that stands out, and will continue to have the most resonance, was her work to promote disability inclusion in the SCHF which carried on through the full duration of her deployment. The SCHF supports the activities inside Syria of about 100 implementing partners per round of funding. Over the course of several funding cycles the prominence of disability inclusion in the SCHF gradually increased, especially once the proposal assessment "score card" was revised to sharpen how disability inclusion was reflected in submissions. In this very competitive funding environment implementing partners had a great incentive to make their proposals as responsive as possible to the SCHF strategy.

Project proposals that used more disability inclusive language would be an empty achievement without positive change on the ground however. Working together with the Deputy Protection Cluster Coordinator in Northwest Syria, who provided a foundation and context for the contributions made and tactical advise on implementation strategy, the Inclusion Specialist helped improve

operations on the ground through the development a "light touch" tool designed to help implementing partners mainstream disability inclusion in their activities by assessing possible attitudinal, institutional and environmental barriers output by output, and then developing appropriate mitigation measures. With the SCHF's full support, an Inclusion Pilot project is currently underway in 2021 with 14 implementing partners to test out and learn from this approach. This pilot program is expected to be evaluated by the end of the year for scale-up in 2022, assuming the SCHF continues.

The case study process led to some contemplation about where in the humanitarian structure this type of technical support is best positioned, given how wide-ranging the Inclusion Specialist's deployment was across different parts of the system. Arguments were made that it was actually best-placed in the Protection Cluster, as it was in Syria. However, others argued that a formal link to the Office for the Coordination of Humanitarian Affairs (OCHA) in the manner of a GenCap advisor made more sense given OCHA's role in the humanitarian program cycle. Others argued that it should be placed directly in the Office of the UN Humanitarian Coordinator, because the proximity this would give to senior humanitarian leadership, and how this would promote greater attention to inclusion issues by the different Clusters. The most common argument heard was in favor of a Disability Inclusion Area of Responsibility, whether under the Protection Cluster or another, such as Health or Shelter.

Flowing from the lessons learned about the Inclusion Specialist's deployment in Syria five recommendations are made:

- 1. **Make the support intervention longer-term.** Define the assignment around a general function description grounded in a specific technical contribution, such as improving the collection and use of disability data, rather than a specific terms of reference. Link the assignment to the humanitarian program cycle approach, from needs assessment through planning, implementation, monitoring and evaluation.
- 2. **The technical assistant should be an expert (not a generalist).** The progress made in the Syria humanitarian community in the area of data collection and use, strategy development, training, and tools development were largely tied to the respect stakeholders had for what the Inclusion Specialist had to offer technically.
- 3. **Focus on operations, rather than system-wide policy.** The outcome from the Syria support intervention that will continue to resonate most will be the Inclusion Specialist's contributions to the SCHF, where disability inclusion was mainstreamed into the strategy, operations manual, proposal evaluation process and, most recently, the Inclusion Pilot. Ultimately the goal of an Inclusion Specialist should be improved programming that benefits persons with disabilities.
- 4. Aim for flexibility to "reach in" to provide direct support across the system. The support intervention should be positioned in a way so as to have space to provide direct support as well as develop practical knowledge products. The various working groups, networks and process leads who invited engagement with the Inclusion Specialist helped generate a demand among Cluster Members and implementing partners for inclusion technical assistance.
- 5. Keep distance from the parent agency. The support intervention should be seen as independent from any one organization's interests so as to avoid the perception of a conflict of interest. The Inclusion Specialist should not be put into a position of having to decide whether to provide support to a system-wide effort versus fulfilling a particular gap in the parent Country Office. Where the support initiative is positioned within the humanitarian architecture may depend on the specific circumstances and opportunities.

Acronyms and Special terms

AAP Accountability to Affected Populations

AIPG Accountability, Inclusion, PSEA and Gender (Strategic Steering Committee)

AoR Area of Responsibility

CCCM Camp Coordination and Camp Management (Cluster)

CERF Central Emergency Response Fund

CLA Cluster Lead Agency

Cluster Clusters are groups of humanitarian organizations, both UN and non-UN, in

each of the main sectors of humanitarian action, e.g. protection, health and

logistics

COVID-19 Coronavirus Disease 2019 FGD Focus Group Discussion

GenCap Gender Standby Capacity Project
HCT Humanitarian Country Team

HI Handicap International, subsequently Humanity and Inclusion

HLG Humanitarian Liaison Group

HNAP Humanitarian Needs Assessment Program

HNO Humanitarian Needs Overview
HPC Humanitarian Program Cycle
HRP Humanitarian Response Plan

IASC (United Nation's) Inter-Agency Standing Committee

ICCG Inter-Cluster Coordination Group IDP Internally Displaced Person

ITWG Inclusion Technical Working Group

Level-3 Response A system-wide mobilization of humanitarian capacity (leadership, staffing

and funding). Level-1 National; Level-2 Regional

MSNA Multi-Sector Needs Assessment

NES Northeast Syria

NGO Non-Governmental Organization

NORCAP Norwegian Capacity, the Norwegian Refugee Council's global provider of

expertise

NWS Northwest Syria

OCHA Office for the Coordination of Humanitarian Affairs

OPD Organization of Persons with Disabilities
ProCap Protection Standby Capacity Project

PSEA Protection against Sexual Exploitation and Abuse

SCHF Syria Cross-border Humanitarian Fund

SCR 2165 Security Council adopted Resolution 2165 which, among other aspects,

allows the UN and its implementing partners to use routes across conflict lines and the Turkey-Syria border to ensure that humanitarian assistance

reaches people in need along the most direct routes

SGBV Sexual and Gender-Based Violence

SRC Syria Resilience Consortium

TDWG Trauma and Disability Working Group
UN DIS United Nations Disability Inclusion Strategy
UNHCR United Nations High Commissioner for Refugees

UNICEF United Nations Children's Fund

WASH Water supply, Sanitation, and Hygiene WG Washington Group (on Disability Statistics)

WHO World Health Organization

WoS Whole of Syria

Contents

BACKGROUND AND PURPOSE	1
METHODOLOGY	1
INTRODUCTION	2
THE DIMENSIONS OF THE SYRIA RESPONSE	2
TIMELINE OF THE SYRIA CRISIS TRACKED DISABILITY INCLUSION REFORMS	
THEORY OF CHANGE	
The assignment of the Inclusion Specialist, and its main outcomes	
OUTCOMES AT THE HUMANITARIAN SYSTEM LEVEL	10
MORE AVAILABLE AND BETTER USE OF DISABILITY DATA	
Interventions contributing to capacity development	
Foundational activities, inputs and factors leading to outcomes	11
OUTCOMES TOWARDS IMPROVED PROGRAMMING	13
CAPACITY DEVELOPMENT OF HUMANITARIAN ACTORS	13
Working Groups	
Accountability, Inclusion, PSEA and Gender: the AIPG Strategic Steering Commi	
Syria Cross-border Humanitarian Fund	
CONTRIBUTIONS TOWARDS REMOVING BARRIERS	
ENABLING STEPS THAT LED TO PROGRAMMING IMPROVEMENTS	
Possible next steps	
Likelihood of sustainability	
CHALLENGES	17
LESSONS LEARNED AND RECOMMENDATIONS	19
Transferrable lessons learned	
FACTORS IN THE SYRIA CONTEXT THAT FACILITATED THE DEPLOYMENT	
PLACEMENT ARGUMENTS FOR AN INCLUSION SPECIALIST	
1. Protection Cluster	
2. Disability Inclusion AoR	
3. OCHA	
4. Humanitarian Coordinator's office	
RECOMMENDATIONS FLOWING FROM THE SYRIA EXPERIENCE	21
ANNEX 1: TERMS OF REFERENCE	23
ANNEY 2. WORTH PEADING	27

Background and Purpose

Humanity and Inclusion has been deeply involved with humanitarian responses to Syria crisis since its onset. It began with interventions to raise the general awareness about disability inclusion among different partners, gradually building trust and relationship with the humanitarian coordination system, towards more focused engagement with the health and protection clusters. Besides directly supporting actions to remove barriers and promoting meaningful participation of persons with disabilities affected by the crisis, in this response HI has also played an important role in improving disability data collection and its use by the humanitarian system.

Part of HI's Syria response has been somewhat unusual, and this is the focus of this case study. HI invested in a dedicated Inclusion Specialist who has closely collaborated with OCHA, the Humanitarian Needs Assessment Program, the Protection Cluster covering Northwest Syria, as well as the Northeast Syria NGO Forum for over two years. The role of the Inclusion Specialist was not spelled out in detail ahead of the assignment. Rather the role allowed the Inclusion Specialist to identify possible entry points and opportunities based on identified needs and gaps, and to use the strong technical background the Inclusion Specialist brought to the role to support a wide range of partners on a demand-driven basis.

The Inclusion Specialist stepped into the role at a time when interest in disability inclusion was growing. Given the violence of the Syria crisis the number of civilians affected by trauma injuries, disability inclusion was a highly visible concern. Already by 2018 the Washington Group short-set questions were being incorporated into humanitarian needs assessment processes by the Humanitarian Needs Assessment Program revealing how much higher the disability prevalence rates were in Syria as compared to global norms. An important value addition by the Inclusion Specialist was sense-making from this data, its interpretation, and the creation of pathways leading to higher quality and more inclusive programming.

The provision of dedicated technical assistance in the Syria response to support inclusive coordination by one person over an extended period of time was a novel approach for HI. However, HI was aware of the model for this type of support elsewhere to other cross-cutting themes and/or approaches like gender, the prevention of sexual exploitation and abuse (PSEA), or accountability to affected persons through global programs like GenCap¹, ProCap² or NORCAP³.

These demand-driven mechanisms plug into humanitarian responses dedicated senior technical advisors to address capacity constraints in humanitarian operations. Evaluations have documented the impact this kind of approach can have⁴. The purpose of this case study is to contribute some background and lessons learned to help steer deployments similar to this one in the future, and make the case for the general importance of this kind technical support to improve disability inclusion in humanitarian action.

¹ GenCap (https://www.humanitarianresponse.info/en/coordination/gencap)

² ProCap (<u>https://www.humanitarianresponse.info/en/coordination/procap</u>)

³ NORCAP (https://www.nrc.no/expert-deployment/aboutnorcap/)

⁴ See Inter-Agency Standing Committee, "Protection Capacity and Gender Capacity: Evaluative Review" (2019).

Methodology

This case study was produced over a period of several months. See Annex 1 for the Terms of Reference. It involved key informant interviews with twenty different stakeholders, including UN staff and NGO staff involved in the Syria response. As a background to these interviews the considerable documentation available on the Inclusion Technical Working Group microsite hosted on the Humanitarian Response platform was reviewed, and this led to the discovery of many other resources, studies and profiles that have been produced (see Annex 2: "worth reading").

The case study also traced how the Syria crisis itself unfolded side-by-side with key milestones where disability inclusion in humanitarian action took place. As well, it analyzed the changing pattern of references to disability inclusion in the Humanitarian Needs Overviews produced for the Syria crisis between 2015 and 2021 that confirmed when interest in this subject blossomed. A similar analysis was done looking at the strategy documents for the Syria Cross-border Humanitarian Fund, as the SCHF was such an important entry point for Inclusion Specialist's work.

Perhaps the most important contribution to the study were the multiple interviews with the Inclusion Specialist, where the experience was laid out on a month-by-month basis describing what actions occurred when, contextualizing some of the decision-making processes that under-pinned the priority setting that took place.

This study is not intended to be evaluative. The choice of the key informants was left to HI to identify. The observations, suggestions and recommendations shared in interviews are not attributed.

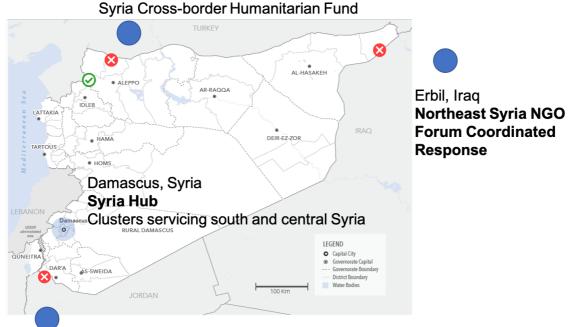
Introduction

The dimensions of the Syria response

The humanitarian architecture around the Syria response is complex. Given that the Government of Syria is itself a party to the conflict, a number of humanitarian response "hubs" have been established to coordinate cross-border humanitarian action (see Figure 1) in addition to the Syria Country Offices the UN and others that remain in Damascus.

Figure 1 Humanitarian Hubs in the Syria Crisis

Gaziantep, Turkey
Cross-Border Humanitarian Liaison Group
Coordinated Response



Amman, Jordan **Humanitarian Country Team Coordinated Response**

Map graphic: Humanitarian Needs Overview, 2018, UN-OCHA

Figure 1 also illustrates where the four crossing points that were originally established as a result of the UN Security Council adopted Resolution 2165 (2014). These were points enabled UN supplies and personnel to cross freely into Syria without the prior approval of the Government. Initially there were four crossing points, but by September 2021, only one crossing remains open, the Bab al-Hawa, on Syria's border with Turkey.

HI's Inclusion Specialist was based in Amman Jordan, the hub where OCHA develops its whole-of-Syria Humanitarian Program Cycle (HPC) products, such as multi-sector needs assessment surveys (MSNAs), humanitarian overviews (HNOs) and response plans (HRPs). However, the Inclusion Specialist also had major interventions with partners working on the Northwest Syria response from Gaziantep Turkey, as well as NGO members of the Northeast Syria Forum from Irbil in Iraq, online initially and ultimately through face-to-face support.

Timeline of the Syria crisis tracked disability inclusion reforms

State violence to suppress popular protests in mid-2011 is said to have triggered the Syria crisis. Figure 2 maps the evolution of the conflict alongside the estimated number of people affected, the



proportion of persons with disabilities in this total, and by the increasing attention to the inclusion of persons with disabilities in humanitarian action.

By 2012 the Office for the Coordination of Humanitarian Assistance (OCHA) estimated the number of persons in need of assistance to be 4 million, plus 729,000 refugees, making it one of the largest humanitarian crises ever. But the number of persons in need rapidly grew. Displacement of the civilian population was one of the defining impacts of the crisis. By 2014 OCHA estimated 7.6 million internally displaced persons within Syria itself. In addition to internal displacement, another defining aspect of the conflict are the huge numbers of Syrians who fled, and sought safety from the violence as refugees. This population has also continued to grow. In 2020 there were about 6.7 million refugees under the mandate of the United Nations High Commissioner for Refugees (UNHCR). For persons with disabilities, sudden forced displacement as a result of conflict poses not only dangers in itself, but also a disruption to livelihoods and dislocation of their network of community support.

A particularly brutal feature of the crisis was the "starve or surrender" strategy, where urban areas were cut off by Government forces, severely constricting what assistance could reach the affected populations. Conflict was made worse by the indiscriminate dropping of "barrel bombs" filled with explosives and shrapnel on urban neighborhoods, as well as the use of chemical weapons. For persons with special needs such as a limited ability to rapidly flee the danger, or those requiring assistance, or persons in need of specialized trauma care, these besiegement tactics are particularly cruel.

2011, the year the Syria crisis began, was also the year when the World Health Organization (WHO) together with the World Bank Group launched the first ever comprehensive World Report on Disabilities, which made a major contribution towards the understanding of disability, and its impact on individuals and society. That report continues to resonate today as it made the first authoritative quantification globally of the proportion of persons living with disability as about 15% of the population. The report also helped shape the understanding of the different dimensions of disability. It may have woken humanitarian actors up to the issue of disability inclusion, who responded to it with new or revised tools and guidance to carry out more effective needs assessments. For example, the UNHCR's Need to Know guidance in 2011, "Working with Persons with Disabilities in Forced Displacement"⁵, was one of the first detailed operational guidance documents for humanitarian actors.

Despite this growing attention paid to persons with disabilities in humanitarian contexts globally, their situation in Syria remained largely invisible. Figure 2 illustrates how from 2011 through 2015 there was no separate disaggregation of persons with disabilities among the estimate of persons in need. Handicap International (later to become Humanity and Inclusion) and HelpAge International undertook ground-breaking research in late 2013 to highlight the number and needs of Syrian refugees in living in Jordan and Lebanon living with "specific needs" estimating that their number exceeded 30% of the affected population⁶. However, the number of persons with disabilities affected by the Syria crisis as a whole was not estimated until 2015, the period when the Humanitarian Needs Overview (HNO) for 2016 was being produced by OCHA, which estimated an 11% overall prevalence rate⁷, this despite the WHO's global estimate of 15% of the population who were assumed to have disabilities, and despite the obvious impact of the increasing frequency of permanent life-altering impairments caused by the conflict. In Figure 2, the orange stripe at the left appears only in 2015, illustrating the persons in need with disabilities, five years into the response.

https://www.researchgate.net/profile/Thomas-

⁵ https://www.un.org/disabilities/documents/WHS/Working-with-persons-with-disabilities-UNHCR-2011.pdf

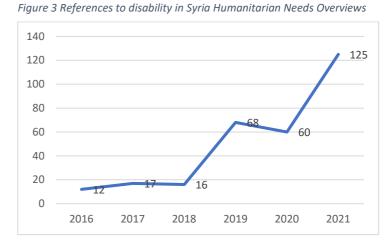
⁶ Specific needs include impairments, chronic disease and injury.

<u>Calvot/publication/262559526 Hidden victims of the Syrian crisis disabled injured and older refugees/links/0deec537f708417cdc000000/Hidden-victims-of-the-Syrian-crisis-disabled-injured-and-older-refugees.pdf</u>

⁷ https://reliefweb.int/sites/reliefweb.int/files/resources/2016 hno syrian arab republic.pdf

Disaggregating the number of persons affected by the Syria crisis with disabilities in the 2016 HNO may have been driven by a number of factors. The 2016 the Global Humanitarian Summit in Istanbul

raised the issue of inclusion of persons with disabilities to prominence with the "Charter on Inclusion of Persons with Disabilities in Humanitarian Action". This momentum triggered the United Nation's Inter-Agency Standing Committee (IASC) to establish a Task Team to begin developing specific inclusion guidance. In 2016 UNICEF also began developing its "Including Children with Disabilities in Humanitarian Action" guidance to begin operationalizing what specific



actions were required to be more inclusive of disabilities in a humanitarian response, and this was released later in 2017. In 2018 specific guidance was being developed to support disability inclusion in Humanitarian Response Plans.

This rapidly growing interest in disability inclusion can be crudely tracked over this period by tracing the number of references to disability in the Humanitarian Needs Overviews for Syria released by OCHA. Figure 3 maps this trend. Interest suddenly grew in 2018, when analysis was underway to prepare the 2019 HNO. A key driver in 2018 for this interest in disability inclusion most certainly was data released that year by the Humanitarian Needs Assessment Program, or HNAP.

HNAP is the joint UN assessment initiative which conducts sector and multi-sectoral assessments, and monitors humanitarian needs inside Syria. The HNAP is implemented through local Syrian NGO partners, with technical support from UN agencies. In June 2018 HNAP began using the Washington Group short-set questions for that year's Syria Demographic Survey. This was the first ever use of the Washington Group short set questions at this scale in an on-going humanitarian crisis. The disability disaggregated data in the Syria Demographic Survey fed into the needs assessment process in 2018, which led to the 2019 HNO where Figure 3 illustrates the sudden surge of references to disability.

This sets the stage for HI's investment in a dedicated Inclusion Specialist who was assigned in late 2019. By coincidence, just as the Inclusion Specialist began the assignment in Syria, the IASC Guidelines on the inclusion of persons with disability in humanitarian action were formally launched.

Theory of Change

This case study will examine the contribution of the Inclusion Specialist made at two levels: promoting change at the level of the humanitarian system, as well as providing direct support to operational actors. A significant pathway for these changes were efforts to improve inclusive programming on the ground, with WASH cluster members in particular, and through local partners funded through the Syria Cross-border Humanitarian Fund. The conceptual model that linked these two levels was the Theory of Change developed by the Inclusion Technical Working Group shown in Figure 4.

Deeply embedded in the Theory of Change are the four "must-do" actions that provide the scaffolding for the IASC Guidance:

• Promotion of meaningful participation by persons with disabilities

Strategic Objective

To operationalize inclusion mechanisms in the humanitarian response

Ultimate Outcome Persons with disabilities and their caregivers have access to humanitarian services in line with their needs, on an equal basis with others



Immediate

Outcomes

Humanitarian community ensures:

- Meaningful participation
- 2. Barriers are removed
- 3. Persons with disabilities empowered
- Descriptive data collected and applied

Persons with disabilities:

- Through consultation and leadership, shape response
- Can access all services and assistance
- Are active participants, users, and service providers
- Are not invisible in statistics and benefit from services

Coordination

Accessible Services Staff Capacities



Participate in platforms from community to strategic level

- Act in accordance with basic rights Access information on available
- services
 - Enabled to participate in all phases of the humanitarian program cycle
- Consult, participate in and lead capacity development programs



- Facilitate participation of persons with disabilities
- Contribute to inclusion mainstreaming
- Promote communication between organizations
- Provide accessible information
- Engage in structured identification of barriers and facilitators
- Raise awareness to improve access, reduce stigma and mitigate risks
- Carry out accessibility audits

- Ensure staff at the field level are equipped with an inclusion mindset, skillset and toolset
- Staff at all levels make informed decisions about inclusive programming

Data and evidence base: assessments; monitoring and evaluation; structured identification of barriers and facilitators Funding and operations: funding allocated in grants to inclusion; appropriate staff; realistic implementation targets; accessibility measures in offices; promoting the twin-track approach to inclusive programming

Guiding **Principles**

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



Inputs and

- Remove barriers
- Empowering persons with disabilities and supporting them to develop their capacities
- Disaggregating data for monitoring inclusion

The central focus of this Theory of Change is at the Outcome level, looking at three dimensions at the level of humanitarian responders and persons with disabilities:

- Coordination to promote the meaningful participation of persons with disabilities
- Provision of accessible services by removing barriers to persons with disabilities receiving needed services
- Building capacities of persons with disabilities and humanitarian partners to empower their engagement

Cross-cutting across these three pillars is work to strengthen the data and evidence base through the collection and use of disability disaggregated data.

These four areas are the IASC Inclusion guidance's four "must-do" actions. One way to think about the Inclusion Specialist's assignment is that it has been an investment towards operationalizing the IASC disability inclusion guidance.

The assignment of the Inclusion Specialist, and its main outcomes

The assignment and original terms of reference were envisaged as a support to the World Health Organization-led Syria Health Cluster, with a specific focus on technical support in the area of rehabilitation care. Given this framing (and funding) the obvious entry point for her in 2020 was Northwest Syria based in Gaziantep Turkey, where HI had long been active, and where the Trauma and Disability Working Group (TDWG) under the Health Cluster had already been established.

Initially, there was no clear long-term objective or Theory of Change for the Inclusion Specialist's role, apart from providing support to improving rehabilitation services through the WHO-led health cluster. The direction was reoriented in February 2020 when demands for disability inclusion support were voiced by the Protection Cluster and its partners. At the same time, the first in-person meetings of the TDWG attended by the Inclusion Specialist clarified that its work was more oriented towards medical responses to injuries caused by the conflict and services along the bio-medical "trauma pathway" that included blood banks, surgeons and physiotherapy. While those were all important issues, they were having less of a mandate and interest on disability inclusion in the humanitarian response from a rights-based perspective, as described in the Convention on the Rights of Persons with Disabilities. Hence, the Inclusion Specialist's support shifted fully to work with the Protection Cluster and other coordination structures.

Approaching disability inclusion in the Syria response from a rights perspective, the Inclusion Specialist had a more generous welcome by the Protection Cluster in the Northwest Syria hub who had ambitions to set up an Inclusion Technical Working Group (ITWG). The HI Inclusion Specialist and the Deputy Protection Coordinator, established this group among interested Members in February 2020.

Fortunately, the Inclusion Specialist's initial face-to-face meetings in Gaziantep in late 2019 with the Protection Cluster managed to find significant common ground. Working relationships were established with the Protection Cluster team, as well as the implementing partners interested in participating in the ITWG. But just as the initial next steps were being defined, the world was plunged into uncertainly by the global COVID-19 pandemic. Travel to support field work was suddenly put on hold.

This apparent set-back was converted into an important opportunity. The Inclusion Specialist's technical background was applied to quickly develop recommendations and advice for providing humanitarian support to persons with disabilities in this new and largely unknown COVID-19 context. Simple guidance was rapidly produced and disseminated under the auspices of the ITWG,

targeted at field workers. In the absence of other materials being available to support the response in this circumstance, the ITWG gained an audience among Northwest Syria implementing partners, as well as immediate relevance.

The Inclusion Specialist's assignment can be visualized as supporting several different processes from in parallel (see Table 1). Some of this support occurred simultaneously. For example, support to the OCHA HPC process started in 2019 and continued on a demand basis through June 2021. With other interventions there was a definite sequencing. Detailed involvement with HNAP on data analysis provided a foundation for advocacy to the NW Syria Inter-Cluster Coordination Group (ICCG). Progress with NWS ICCG was an important foundation for the quick wins with the NE Syria Inter-Sector Working Group, when a formal NES inclusion strategy was established under the group in January 2020 and it became possible to travel to that area in June 2021, as the basic presentation format and training materials developed earlier only needed to be adapted in order to be relevant to the NE Syria context. Similarly work with the Syria Cross-border Humanitarian Fund (SCHF) began in late 2019 but only began to show strong progress in 2021.

Table 1 Important Outcomes from the Inclusion Specialist's Assignment to the Syria Response 2019-21

Hub	Partner	Pathway	Important Outcome
Whole of Syria	OCHA	Humanitarian Program Cycle (HPC)	Development of an Inclusion Strategy for the 2021 Humanitarian Response Plan
	Humanitarian Needs Assessment Program	Collection and analysis of disability disaggregated data	Use of the Child Functioning Modules in the nationwide Household Survey in 2021, support to Disability Overviews, forthcoming Gender, disability and Age report
Northwest Syria	Health Cluster	Trauma and Disability Working Group	Offered training and support, but little uptake or interest by stakeholders
OC	OCHA Turkey	Syria Cross-border Humanitarian Fund	Mainstreaming disability into the proposal review process
			Development and piloting of guidance and tools for the inclusion pilot project to identify barriers and mitigation measures
		Inter-Cluster Coordination Group	Awareness of humanitarian actors for improved inclusion of persons with disabilities, most notably by the WASH Cluster
	Protection Cluster	Inclusion Technical Working Group	Dissemination of tools, guidance, a technical webinar and research (notably on the lived experience and perspectives of IDPs with disabilities)
	Leadership Group	AAP, Inclusion, PSEA and Gender (the AIPG) Strategic Steering Committee	Amendment of SCHF allocation processes, the score card, indicators and revisions to the operations manual
	WASH Cluster	Gender Focal Point role	Review of guidelines, operational procedures

Hub	Partner	Pathway	Important Outcome
Northeast Syria	Northeast Syria Forum (NES Forum)	Inter-Sector Working Group	Orientation and increased awareness of partners, particularly camp managers; capacity for improved assessments
			Provided training on inclusive camp registration and population monitoring for staff working in ten camps across Hassake and Raqqa Assessed three camps (using key informant interviews, focus group discussions and observation assessments) and produced a report including an analysis of barriers and recommendations for better alignment with the IASC guidelines

The following sections will look at these Outcomes at the level of the Syrian response as a whole, and at the field level where improvements to programming took place.

Outcomes at the humanitarian system level

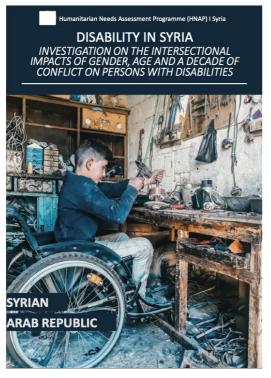
The IASC guidelines on the inclusion of persons with disability in humanitarian action that were launched right at the outset of her assignment provided a backdrop for many of the contributions the Inclusion Specialist made at the system level. Following the launch of the IASC guidelines, there was a not-so-gentle push by some donors and the Humanitarian Relief Coordinator to pay more attention to disability inclusion, and this was certainly an enabling factor that allowed the Inclusion Specialist's work to proceed.

More available and better use of disability data

Early progress towards more available and better use of disability data had already been seen in the Syria response prior to the arrival of the Inclusion Specialist on the scene. But the contributions the Inclusion Specialist made to interpret the data added to the momentum that already existed at the system level, following the decision to institutionalize the Washington Group short-set questions by HNAP. Key informants to this study reported clear effects at the system level now that this disability data exists and is in use.

Given the unexpectedly high disability prevalence rate that the HNAP data signals, there is now much greater receptivity towards complementary qualitative data. The ITWG produced a report describing the self-reported barriers to activities of daily living of persons with disabilities living in

Figure 5 Forthcoming Analysis of Intersectional Impacts



IDP sites in northwest Syria. This type of evidence based on the lived experiences of persons with disabilities, using their direct testimonies, is all the more powerful because of the availability of underlying quantitative data provided by HNAP that confirms the huge scale of the issue.

With more available data, analysis can go deeper. HNAP's forthcoming intersectional analysis (Figure 5) looking at disability issues in relation to gender and age is an example of how, by having the data, better analysis can be performed about household livelihoods, security and education.

Great progress has been made towards the standardization of disability data by HNAP using the Washington Group approach. Disaggregated analysis is now possible by population group. The availability of disability disaggregated data by different population groups (IDPs, returnees, female headed household heads, etc.) has contributed to a shifting of attitudes about disability by programmers in different sectors. This has led to more interest in operational settings, such as the WASH Cluster, to inform response planning and implementation.

Interventions contributing to capacity development

A constraint identified by some key informants was that the IASC inclusion guidance was missing orientation and training materials to put it into practice. This prevented its rapid uptake by mainstream actors. With the Inclusion Specialist's support, ITWG helped fill this gap with a number of short, practical tools that made the IASC guidance more accessible to local organizations. The ITWG's note on disability-inclusive project design and its position paper on the importance of disability data were considered very useful contributions in the response community.

Developing a Theory of Change (Figure 4) contributed to a broader and shared understanding about how to achieve disability inclusion in humanitarian action in the Syria context. It helped mainstream humanitarian actors to recognize what they needed to do along the different pathways to operationalizing inclusion mechanisms.

Members of the ITWG also appreciated the Inclusion Specialist's active "curation" and distribution of scientific materials, assessment reports and updates through ITWG meetings.

The Inclusion Specialist provided training-of-trainer support to HNAP survey teams. This process involved fine-tuning the translation of the Washington Group questions. It also involved developing materials to orient enumerators to the social model of disability in an attempt to shake existing cultural biases prevalent in Syria about disability. Now each time the survey is repeated there is an increasingly widespread understanding of the disability concept.

Of course, based on these materials, and in a needs-responsive manner, the Inclusion Specialist provided a considerable amount of direct technical support, starting with virtual trainings and webinars related to the COVID-19 pandemic response, and how to recognize the risks posed to persons with disabilities while remaining inclusive to their needs. Other "hands on" support was provided more directly to humanitarian actors. For example, comments have been provided on all submissions to the Syria Cross-border Humanitarian Fund via the Inclusion Specialist's participation in the strategic and technical review committee which scored these proposals. Support was provided to revise the new arrivals questionnaire where basic data is collected on displaced people arriving in IDP camps. Technical training was provided in areas such as health and hygiene management during COVID-19 for people with health conditions.

Foundational activities, inputs and factors leading to outcomes

The Theory of Change identifies three key factors at the activity and input level: an improved data and evidence base, funding as an enabler and as an incentive, and the greater attention to programming.

At the system level, access to **more and better disability data** was obviously a key foundation stone necessary to achieving the other outcomes. Cluster leaders were initially quite skeptical about the high disability prevalence rates being reported by HNAP. The data startled humanitarian actors about the broad dimensions of the disability issue.

The subsequent addition of the Child Functioning Module with the support of the Inclusion Specialist was an important step. Without data describing the disability context for children and adolescents, many humanitarian actors would not have the information they required to advocate with donors, raise resources and develop responsive programs.

Second, the Inclusion Specialist helped support the mainstreaming of disability inclusion into the check-list used by the SCHF to "score" proposals submitted for funding. This intervention was a powerful **incentive**, but required several funding cycles to complete. In the very competitive funding context implementing partners are keen to ensure their proposals were being fully responsive to the SCHF strategy. Key criteria added to better reflect disability inclusion therefore led implementing partners towards filling these gaps.

Third, and this continues to be a work-in-process, the Inclusion Specialist has provided support to implementing partners about how to practically make programming more inclusive is critical. Many key informants mention the potential gap between saying the right things and using inclusive language in proposals, and making actual changes on the ground with their activities. The Inclusion Specialist focused on three things:

• Investing time in processes to mainstream disability across the SCHF strategy to influence changes in the proposal assessment system,

- Working with third party monitors to educate them about how to assess the implementation of activities for a disability inclusion perspective
- Providing direct support to implementing partners to identify barriers (and facilitators) to inclusion in the activities they undertake

A number of personal professional qualities were also cited, such as the Inclusion Specialist's technical background, that contributed to the many outcomes being achieved at the pace they were in 2020 and 2021. Being able to convey technical material in a credible, clear, accessible and practical manner facilitated effective uptake. And despite working on multiple initiatives simultaneously, the Inclusion Specialist was also able to provide individual advice to implementing partners quickly, which was highly appreciated by partners.

At the global system level, revisions to the Humanitarian needs assessment methodology beginning in 2020 that put greater emphasis on intersectoral analysis and the definition of the severity of need were important enablers to her work. These changes led Clusters to re-examine their context in a way that required the type of very granular and disaggregated data that HNAP was providing. The Inclusion Specialist could very credibly explain what seemingly counter-intuitive data was saying.

Ironically the COVID pandemic also helped lead partners down a path leading to positive outcomes. When face-to-face meetings became impossible, the Inclusion Specialist was able to "market" key inclusion concepts wrapped up in COVID guidance. In the early days of the pandemic there was initially a high demand for clear advice, and this was something the Inclusion Specialist was well-equipped to provide quickly.

The capacity of the Protection Cluster in Turkey due to the Level 3 scale-up response, and their interest in the issue of disability inclusion were also a factors leading to success. The Inclusion Specialist and the Deputy Protection Cluster Coordinator made a good team with a very positive working relationship. This strong institutional backing provided the Inclusion Specialist with entry points into the humanitarian community that would not have otherwise existed. The Protection Cluster team was able to provide tactical advice about how material should be presented, to whom, and the most appropriate ways of getting the work done.

Outcomes towards improved programming

Capacity development of humanitarian actors

Working Groups

In Northwest Syria the Inclusion Specialist has been engaged to a varying extent with four different groupings: the Health, Protection and WASH Clusters, and as an invited contributor to the Inter-Sector Coordination Group. The most sustained progress was achieved with the Inclusion Technical Working Group under the Protection Cluster, which produced dozens of products in the 2019-2021 period. The least progress reportedly was made with the Trauma and Disability Working Group under the Health Cluster, although the Inclusion Specialist continued to respond to requests for assistance by its Members.

Sustaining momentum and the broad-based participation in these kinds of groups is challenging. Members of the ITWG report that by taking part they gain access to materials and resources that they would not otherwise have had access to. But key informants also report that sometimes their major investments in time in these processes do not result in a significant benefit.

Travel restrictions during the COVID pandemic limited the engagement by the Inclusion Specialist with the Northeast Syria NGO Forum in 2020. However, as restrictions loosened in 2021 the Inclusion Specialist was able to apply the same approaches used in NW Syria to the engagement with partners in the NES Forum. An introductory presentation made to its Inter-Sector Working Group led to requests for further follow-up support from the WASH and Camp Coordination and Camp Management sector.

Accountability, Inclusion, PSEA and Gender: the AIPG Strategic Steering Committee

Advisory roles in cross-cutting areas like disability inclusion are challenging while what advisors have to say is important and relevant to all Clusters, they have no role authority over these bodies. Accountability, Inclusion, PSEA and Gender advisers float somewhere in between management and field operations. Unless invited into a process, they remain on the outside looking in.

In NW Syria Humanitarian Liaison Group (HLG) a solution to this was found by creating a strategic steering committee made up of the advisors in these four cross-cutting areas. For each area an advisor or focal point was identified, and this group worked together with a mandate to provide strategic advice to the HLG. The AIPG met for the first time in 2021 under the co-chair leadership of UNICEF and Humanity and Inclusion.

Although its actual role remains somewhat ambiguous, having the AIPG Strategic Steering Committee in place has greatly facilitated progress with inputs to the SCHF strategy, its scoring system and the Inclusion Pilot project. The AIPG committee provides advice to the Deputy Humanitarian Coordinator in Gaziantep, who sits on SCHF Advisory Board. In other words, the AIPG committee gives advisors on these cross-cutting themes a voice at senior management levels, letting them get past the filter of Cluster management, who tend to represent their own technical interests first, above cross-cutting issues.

Syria Cross-border Humanitarian Fund

There was a lot of interest in disability inclusion during 2019. Figures 2 and 3 above illustrate how that year was a turning point for disability inclusion, driven by several factors including the release of the IASC guidelines on the inclusion of persons with disability in humanitarian action. In April the UN Under-Secretary-General for Humanitarian Affairs and Emergency Relief Coordinator (ERC) announced a framework for a \$125 million allocation to Central Emergency Response Fund (CERF) in 2019 that would include disability as one of four additional priorities that would "steer" allocations.

Although the Syria Cross-border Humanitarian Fund is not part of the CERF, and so was not formally influenced by ERC's "four steers", it is also managed by OCHA, and it does receive funding from the same donors who were supportive of the announcement. As a result, in 2019 there was an incentive for the SCHF to raise the profile of disability. OCHA management asked the Inclusion Specialist to provide support to mainstreaming inclusion across the so-called "standard allocation strategy" of the cross-border fund. Figure 6 illustrates a count of references to disability inclusion in these programming documents from 2014 through 2021. In a similar pattern to that observed with the HNOs for Syria, the number of references to disability issues shot up in 2019, likely the result of more and better disability data becoming available, and also because of the global attention being paid to the topic.

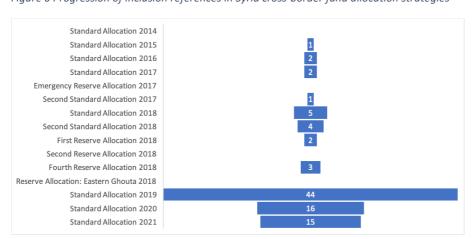


Figure 6 Progression of inclusion references in Syria cross-border fund allocation strategies

The standard allocation is funding that is made available by OCHA to support programming by implementing partners. In the case of NW Syria, this is a cross-border operation managed out of Gaziantep Turkey, targeted towards affected populations inside of Syria. The standard allocation strategy is an important guidance document as it signals to potential applicants what kinds of project proposals would be funded. For the first twelve standard allocation strategies, from 2014 to 2018, disability inclusion was only mentioned in passing, often only as one criterion in a long list of vulnerability criteria.

Figure 6 illustrates how in 2019 disability inclusion was suddenly very prominent. However, while it had a higher profile rhetorically, the standard allocation strategy and the SCHF provided no tools or resources to help support implementing partners to actually do anything practical about increasing inclusion. The language of proposals from implementing partners in 2019 may have used the right words more often, but without technical support to make project design and field activities more inclusive, not much changed on the ground in 2020.

The newfound attention to disability inclusion starting in 2019 did provide an opportunity for change, and three approaches were used.

The first focused on monitoring. HI had been invited by a donor to develop a more inclusive framework for cross-border third party monitors to use in order to independently assess project implementation taking an enhanced disability perspective. Monitors would assess what was going on in the field and bring back evidence about how disability inclusive projects actually were. This undoubtedly had an influence on the SCHF, whose projects would be covered by this more disability inclusive monitoring approach.

Second, the Protection Cluster and the Inclusion Specialist were included in a process to revise the "score card", the basic tool used by the SCHF to review project applications. The funding environment in the Gaziantep hub was extremely competitive. The SCHF awards money to NGOs based on a comparative assessment of all the proposals received in terms of how responsive they

are to the standard allocation strategy. A panel of independent reviewers all use the same score card tool when they review proposals. So by tweaking how points were awarded to proposals in this process, implementing partners were incentivized to present more specific ideas about how disability inclusion would occur in their projects.

The third approach that the Inclusion Specialist contributed to was perhaps the most significant. The idea was to provide direct technical support to implementing partners requesting it to make their projects more disability inclusive in practice. The Inclusion Specialist helped develop what was called the Inclusion Pilot project in 2021. Among the approximately 100 SCHF awardees, 14 volunteer organizations took part to analyze the existing barriers to inclusion in their activities, and design mitigation measures. A key tool in this process was "The Matrix".

Figure 7 illustrates an example of how the inclusion analysis would be done. Implementors were guided to examine each output they describe in their project results framework, looking for potential attitudinal, environmental and institutional barriers to the inclusion of persons with disabilities. These barriers are then examined relative to the four "must do" actions described by the IASC disability inclusion guidelines to work out an approach to remove the barriers identified. The ITWG had earlier defined a disability-inclusive project design brief that was aligned to this tool, which offered many possible mitigation approaches.

Figure 7 "The Matrix": Syria Cross-border Humanitarian Fund Inclusion Pilot

			Sh.
BARRIERS Identified / foreseen / potential factors in a person's environment that hamper participation and create disability, limiting access and enjoyment of the project outputs	Possible attitudinal (community) barriers	Possible environmental (physical) barriers	Possible institution (organization, local entries) barriers
Project output 1 – providing services to the affected population	Stigma and discrimination occurring in the environment where the project operates Risks of exploitation in the environment where the project operates Risks of abuse (including GBV) in the environment where the project operates Risks of discrimination, exploitation and/or abuse by other project participants Exclusion and discrimination by project staff	No ramps Unpaved roads Uneven terrain Accessible toilet facilities for males and females with diverse difficulties are not available Accessible transport is not available including for a care giver to access the project Distributions - safety and accessibility of distribution points is not assured; buddy systems for safe distributions not available	Lack of awareness of organital staff Lack of skills of staff De facto local authorities do not ensure inclusion measures are taken into account in processes relevant to humanitarian action
MITIGATION MEASURES	Approach to remove attitudinal barriers	Approach to remove environmental (physical) barriers	Approach to remove institutional barriers
Project output 1 – providing services to the affected population	Consultations with persons with disabilities will be conducted and documented Community engagement will be conducted, including to raise awareness of capacities of persons with disabilities	All project buildings will have access ramps Accessible toilets will be included in all project locations Accessible transport will be provided to ensure access to the service	All project staff will receive training on inclusion All staff sign a code of conduct that explicitly mentions inclusion and disability awareness Monitoring / data collection will be conducted applying full disaggregation, ensuring gaps are identified and corrective measures can be taken

Evaluation resources have been put in place by the SCHF in 2021 to assess how well projects receiving support from the Inclusion Pilot project did in terms of improving disability inclusion in their activities. Based on this learning, if the SCHF continues, the idea is to make this type of analysis a mandatory part of the standard allocation process in future.

Contributions towards removing barriers

The Inclusion Pilot project was a very central contribution to removing barriers operationally, key informants identified other areas (Table 2) where contributions were made to remove barriers at the organizational level.

Table 2 Where contributions were made to remove attitudinal, environmental and institutional barriers

Attitudinal barriers	HNAP data has been used as an entry point for the Inclusion Specialist to raise awareness among implementing partners and Cluster Members about the different dimensions of inclusion, and how an impairment only becomes a disability when barriers are put in place.
Environmental (physical) barriers	When the Protection Cluster has reviewed what needs to be done to encourage greater participation by local organizations, communication was raised as a major barrier. In the ITWG steps have been taken to ensure Arabic language interpreters, and the translation of materials and resources.
	In 2019 persons with disabilities were invited to participate in a working group meeting that was organized in a physically inaccessible room. This immediately raised the awareness of Members of the working group around the issue of physical barriers. The COVID-19 pandemic and remote working arrangements mitigated some of the physical barriers to participation but also raised awareness about potential accessibility constraints in other activities, such as remote education and the collection of household survey data.
Institutional barriers	Inclusive humanitarian action was perceived by implementing partners and donors as being "too expensive". The ITWG conducted a study involving key informants with disabilities and learned about their perspectives on barriers to receiving humanitarian assistance. This has resulted in new openness to support budget lines that are more inclusive, such as providing transport allowances to participants with disabilities, whereas previously these lines would have been cut from final budgets.

Enabling steps that led to programming improvements

Eight enabling steps took place in the Syria experience and might be generic enough to inform future deployments.

- 1. The Inclusion Specialist found an institutional "home base" to work from. In northwest Syria, this was with the Protection Cluster, where together with the Deputy Protection Coordinator an Inclusion Technical Working Group was established.
- 2. Early in the deployment the Inclusion Specialist delivered some "quick wins" with recognized value related to how partners could ensure a more inclusive response to the COVID-19 situation. Their dissemination served to raise the profile of the role, and helped generate demand for other the support could be provided.
- 3. By using the coordination structures that were already in place, the Inclusion Specialist identified pathways and workstreams that helped to practically operationalize the IASC disability inclusion guidelines.
- 4. The Inclusion Specialist maximized the use of existing disability data through better interpretation and analysis.
- 5. A Theory of Change development process helped get different stakeholders pointed in the same direction strategically. The Theory of Change was a good example for how the IASC disability inclusion guidance provides a framework for a common strategy.
- 6. A position statement was developed together with the Protection Cluster that highlighted the importance of disability disaggregated data to help persuade Cluster members about the

- importance of better data. Following up on the position statement, the Inclusion Specialist was also well-positioned to provide sector-specific technical support, such as revising IDP registration processes, or innovating and testing accessibility audits.
- 7. Because of the opening provided by the SCHF, the Inclusion Specialist was able to influence improvements to programming on the ground.
- 8. Engagement with the humanitarian needs assessment process beginning in 2019 when global attention that was being paid to the issue of disability inclusion. IASC Humanitarian Program Cycle guidance now pushes Clusters to think harder about the intersection between disability and other household vulnerability factors. This was an area where the Inclusion Specialist's contributions were particularly well-received.

Possible next steps

A gap still remains between the more inclusive Humanitarian Needs Overviews that have been produced in Syria since 2019, and the Humanitarian Response Plans (HRP) that follow them. The HNOs identify the needs and their scale, but so far HRPs in Syria do not include any measurable indicators that confirm whom the programming is reaching. In other words, the improved analysis is not followed up in a significant way by more inclusive programming as yet. While the Inclusion Pilot Project is an excellent first step to change this, it needs to be scaled-up and applied far more widely.

More and better disability data disability disaggregated data exists, but some operational data collection mechanisms are not well-aligned to it. For example, in Syria, the HNAP study of IDPs using the Washington Group short-set questions estimated that 37% of the population above the age of 12 experience disabilities. However, the Camp Coordination and Camp Management Cluster in the 2021 Humanitarian Needs Overview, using its own camp registration data, estimates the proportion of persons with disabilities in need as only 2%.

Finally the lessons coming out of the Inclusion Pilot need to be carefully documented so the approach can be adjusted and scaled-up widely in the Syria response, or even globally.

Likelihood of sustainability

Key informants to the case study were asked to provide their perspectives on the future which are organized here as facilitators for disability inclusion being sustained, and barriers.

Facilitators

- There is a high level of interest, and possibly also a commitment to disability inclusion by Cluster Members
- A greater awareness of the disability concept exists
- Checklists, guidance documents, tools and standard operating procedures are now in place, and are easily accessible

Barriers

- High turnover of humanitarian staff demands a process of continual retraining
- SCR 2165 which authorizes cross-border support by the UN is set to expire, and if it does, the SCHF modality might disappear
- Operational tools like checklists and procedures may not yet be sufficiently embedded and mainstreamed
- It may be too soon for the "disability inclusion mindset" to have been consolidated, as it comes up against deep cultural biases
- The absence of on-going and institutionalized support in the system

Challenges

Key informants to this case study offered several persistent challenges or barriers experienced by humanitarian actors in Syria to undertake programming more inclusive of persons with disabilities:

Attitudes of humanitarian actors. "Why do something when you have no expertise, no money, and you might fail?" Several key informants described disability inclusion as yet another "thing" to pay attention to, in a growing list of cross-cutting issues that humanitarian actors have to consider. While these attitudes may not be unique to the Syria context, they present a hidden but persistent challenge to more inclusive programming.

Impacting the broader humanitarian response. The Inclusion Specialist's experience shows how a program like the SCHF can be influenced to achieve positive changes. Of the fifteen Standard Allocation strategies for NW Syria that were reviewed, they averaged about \$25 million per round. And while this is no doubt a lot of resources to support the cross-border program, the overall Syria response each year has averaged about \$4 billion. Influencing change may be easier for a \$25 million program than to prioritizing disability inclusion across the broader humanitarian response.

Defining appropriate targeted disability inclusion programming models. The Matrix project design exercise used in the Inclusion Pilot identifies barriers and facilitators to disability inclusion in mainstream activities. But a portfolio of targeted disability project types that can be implemented at scale in a humanitarian context has yet to be defined.

Disability disaggregated data. Using the Washington Group short-set questions do add some complexity to implementing household surveys, requiring slightly more time for administration, as well as the need for training prior to use.

Technical support. The IASC guidelines on the inclusion of persons with disability in humanitarian action provides a very useful, sector-by-sector framework for more inclusive programming. While the GenCap advisors are on stand-by to strengthen capacity and leadership of humanitarians to undertake and promote gender-sensitive programming, there is no similar facility in place to promote disability inclusion.

Inter-Sector Coordination. The organization of the Syria response with its different "hubs" and coordinating mechanisms resulted in some standardization issues, for example with the CCCM Cluster as discussed above. Targeting criteria, for example, are not the same across different sectors and Clusters.

Lessons learned and Recommendations

Transferrable lessons learned

Future assignments should be designed from the outset as long-term, 24–36-month deployments. Progress with the SCHF was successful but this outcome did require two years in order to gain traction, and the Inclusion Pilot has not yet been evaluated and scaled-up.

Assignments such as these require flexibility to define where exactly the opportunities and entry points are, what needs to be done, with whom and how. Resilience is also a useful trait in an ambiguous assignment where the goals are not stated (or may change), where the assignment duration is not fixed, and where a high degree of personal initiative is required.

Developing a Theory of Change was a powerful approach to get different stakeholders aligned. The current GenCap global methodology uses a "roadmap" method, a type of results framework, that tries to achieve the same kind of alignment, helping manage the contributions of different stakeholders and keeping the process accountable.

Prior experience with humanitarian programs and processes proved less important in this deployment than people skills, and the ability to work in teams. The Inclusion Specialist provided technical contributions that were steered and targeted by the non-technical Deputy Protection Cluster Coordinator who had very strong organizational savvy, and who was able to fine-tune the resources developed for programmers, making them as "light touch" as possible.

The ability to wear different "hats" is important. This might range from back office technical support in an area like questionnaire design and data analysis to a more public-facing advocacy role across a range of different clients, from local authorities and organizations to donors.

Factors in the Syria context that facilitated the deployment

The Syria crisis is complex and protracted. The disability issue for persons in need is highly significant not only because of the prevalence rate of 30% (36% for IDPs) therefore impacting practically every family affected by the crisis in some way, but also because of the huge risks that exist for persons with disabilities due to the nature of multiple displacements that have occurred in the crisis. In another kind of humanitarian response, where the prevalence and of persons with disabilities might not be as high, there might be less openness to disability inclusion.

This deployment was facilitated by the attention that was being paid to the issue of disability inclusion globally from 2016 through to the deployment in 2019, including the launch of the IASC guidelines on the inclusion of persons with disability in humanitarian action at about the same moment the assignment began. This created an enabling environment for inter-agency action, and a launching pad recommendations and training.

The sheer scale of the Syrian Level 3 humanitarian response provided scope for organizational innovation, such as through the SCHF, the AIPG or HNAP.

Ironically the COVID pandemic may have also facilitated the deployment, as it provided an audience among humanitarians for inclusion approaches that may not have existed during a more "normal" time. COVID-19 also diverted the attention of the Health Cluster away from disability in a way that allowed a more livelihoods-oriented approach to be followed through the Protection Cluster.

The complicated humanitarian architecture in the Syria response, with different hubs and spheres of interest, may have also facilitated the Inclusion Specialist moving around and providing operational support where opportunities arose. The multiple hubs also provided an opening for the different coordination structures (NWS, NES, WoS) to learn from each other.

The infrastructure to carry out high quality disability-disaggregated household surveys was already in place, and the first data had been released by the time the Inclusion Specialist arrived. This created an opportunity for continuing support and collaboration with the HNAP to effectively use and apply the evidence immediately, rather than having to support the long process of introducing the Washington Group questions into the household surveys.

Placement arguments for an Inclusion Specialist

In this deployment the Inclusion Specialist had considerable freedom based on identified entry points to support several different parts of the Syria response simultaneously, but a valid question to ask is where the optimal placement would be more generally. Although the actual humanitarian structure supporting the Syria response was a lot more complex, Figure 8 illustrates the basic architecture.

UN Under-Secretary-General Inter-Agency Steering for Humanitarian Affairs and Emergency Relief Coordinator 4 Global Cluster Lead Agencies UN Office for the UN Humanitarian Coordinato rdination of Humanitariar Humanitarian Country Team Affairs Cluster Lead Agency Chief of Mission Protection Cluster Specialized Areas of Responsibility: Cluster Coordinator Child Protection Gender-Based Violence Housing, Land and Property Mine Action · Disability Inclusion Adapted from OCHA, "Who Does What?" Cluster Members Implementing Partners https://www.humanitarianresponse.info/en/c oordination/clusters/who-does-what

Figure 8 Generic Humanitarian Response Architecture, spotlighting four points to situate Disability Inclusion

Key informants had a variety of perspectives on this issue which are summarized below.

1. Protection Cluster

In the Syria crisis response disability inclusion was informally fit into the Protection Cluster where an Inclusion Technical Working Group was established for Cluster Members. The Inclusion Specialist became a co-Chair of the ITWG and this provided some degree of institutional context. This positioning clearly grounded the Inclusion Specialist's work operationally, and was appreciated as the Cluster Members needed the technical assistance but would not be able to afford to bring in these specialized skills on their own.

Practically, the arrangement of embedding with the Protection Cluster worked effectively in Syria as its stakeholders welcomed the role of the Inclusion Advisor.

2. Disability Inclusion AoR

Like the issue of protection, "inclusion" is not a sector itself, but cross-cuts across all the other sectors.

The Sexual and Gender-Based Violence Area of Responsibility (SGBV AoR) is a possible model arrangement for how disability inclusion could be advanced. The foundation for the SGBV AoR is a

specific IASC guidance for how to integrate GBV interventions across all Clusters in a humanitarian response that follows the same format as the disability inclusion guidelines. The UN Population Fund is the lead agency for the SGBV AoR.

The argument for establishing disability inclusion in the same way as the SGBV AoR, is that the issue needs to be on par in the humanitarian hierarchy with other Cluster Coordinators. Humanitarian actors understand what an AoR is, and how the system works. There are numerous processes where Coordinators work together, for example in developing a shared results framework in the Humanitarian Response Plan. A Disability Inclusion AoR would therefore make the disability inclusion issue more institutionalized and visible, making it possible to formally engage in processes.

Similar to the SGBV AoR, the mandate of a Disability Inclusion AoR would be to operationalize the IASC Guidance. However, such a new structure would require a Lead Agency who can commit to raising the necessary resources. While this Lead Agency is most often a UN agency, this is not a requirement.

With the formal status of an AoR, it would also be possible to monitor the achievement of HRP indicators and hold other Clusters to account. The status of an AoR would give Disability Inclusion an entry point into processes like the humanitarian needs assessment process. In the Syria response the Inclusion Specialist was invited by OCHA to join discussions about the Multi-Sector Needs Assessment survey process, as well as to lead in analysis for the Humanitarian Needs Overview, but this was due to the relationships the Inclusion Specialist had built up rather than any formal mandate.

There is presently a proliferation of different AoRs coordinated by the Protection Cluster lead. There would be an argument to situate a disability inclusion AoR elsewhere, for example under the Health Cluster (where WHO is the CLA) or the Shelter Cluster (where the International Federation of the Red Cross and UNHCR are co-leads).

3. OCHA

OCHA facilitates inter-cluster coordination processes, response-wide information management, and it supports humanitarian financing. Its management of the Multi-Sector Needs Assessment process provides an obvious entry point to improve disability disaggregated data collection and use. OCHA also has a say in the inter-operability of data collection methods. It has a technical assistance coordinating role to support Clusters in terms of information collection and dissemination.

OCHA manages the CERF and other Country Based Pooled Funds (like the Syria Cross-border Humanitarian Fund). In the Syria response the SCHF was as very useful channel through which to influence disability inclusion at the operational level.

But OCHA is also explicitly non-technical in terms of operations. Advisors that OCHA hosts, for example GenCap Advisors, are always secondments from some other organization.

4. Humanitarian Coordinator's office

Those making the case to position the Inclusion Specialist in the Humanitarian Coordinator (HC) office argue that it putting it there gives it a kind of power to supervise the broader humanitarian response, going beyond providing advice, due to the close proximity to senior management. An Inclusion Specialist with expertise in the interpretation of disability data positioned next to the HC could have a strong influence on decision-making.

Recommendations flowing from the Syria experience

1. **Make the support intervention longer-term.** Define the assignment around a general function description grounded in a specific technical contribution, such as improving the collection and use of disability data, rather than a specific terms of reference. Link the assignment to the

- humanitarian program cycle approach, from needs assessment through planning, implementation, monitoring and evaluation.
- 2. **The technical assistant should be an expert (not a generalist).** The progress made in the Syria humanitarian community in the area of data collection and use, strategy development, training, and tools development were largely tied to the respect stakeholders had for what the Inclusion Specialist had to offer technically.
- 3. **Focus on operations, rather than system-wide policy.** The outcome from the Syria support intervention that will continue to resonate most will be the Inclusion Specialist's contributions to the SCHF, where disability inclusion was mainstreamed into the strategy, operations manual, proposal evaluation process and, most recently, the Inclusion Pilot. Ultimately the goal of an Inclusion Specialist should be improved programming that benefits persons with disabilities.
- 4. Aim for flexibility to "reach in" to provide direct support across the system. The support intervention should be positioned in a way so as to have space to provide direct support as well as develop practical knowledge products. The various working groups, networks and process leads who invited engagement with the Inclusion Specialist helped generate a demand among Cluster Members and implementing partners for inclusion technical assistance.
- 5. **Keep distance from the parent agency.** The support intervention should be seen as independent from any one organization's interests so as to avoid the perception of a conflict of interest. The Inclusion Specialist should not be put into a position of having to decide whether to provide support to a system-wide effort versus fulfilling a particular gap in the parent Country Office. Where the support initiative is positioned within the humanitarian architecture may depend on the specific circumstances and opportunities.

Annex 1: Terms of Reference

Effectiveness and Functioning of deployment of Inclusion Specialist supporting the Humanitarian System with foci: Quality Data, Coordination, Capacity development

Background

Collecting, analyzing and using data for humanitarian programming is essential to meet the humanitarian needs of persons affected by conflict and natural disasters effectively. Reliable, comparable and robust data on prevalence of affected persons with disabilities, their humanitarian needs, the barriers and risks they face, and their protection concerns have been largely overlooked in the Humanitarian System. This gap has been acknowledged at the Humanitarian Summit in 2016. Since then, an applied research and learning project implemented by IDA, the Washington Group on Disability Statistics and HI in partnership, has demonstrated that the Washington Group (WG) Short Set of Question can help addressing the data gap⁸. Other collective efforts have been done to progress tools on disability specific barriers and risks assessments for integration in existing needs and risk assessments, and monitoring efforts. Importantly, Policy and Capacity developments have been undertaken at global level to support humanitarian actors to better engage persons with disabilities in humanitarian action, namely the IASC Guideline on the Inclusion of Persons with disabilities in Humanitarian Action (2019), Guidance to enhance inclusion of persons with disabilities in the Humanitarian Response Planning (2019), and various Sector specific guideline adaptations.

HI has supported efforts to improve data collection, remove barriers, promote meaningful participation of persons with disabilities and empowerment action as well as capacity development of humanitarian actors in more than 20 humanitarian crises contexts, over the last 10 years. In the Syrian Crisis, among other efforts, it sought to support disability inclusion through strengthening the collection, analysis and use of quality disability data in the humanitarian coordination and programming mechanisms. It did so via capacity development for disability inclusive humanitarian data collection and inclusive programming, including in the Humanitarian Needs Overview (HNO) and Humanitarian Response Plan (HRP) processes across the overall Humanitarian Program Cycle (HPC). It is thought that by providing a human resource who closely collaborated with the Protection Cluster as well as other coordination mechanisms and humanitarian leadership in North East and North West Syria over the last 2 years, that this may have played an important role in improving disability inclusive data collection and creating pathways to quality programming, making the overall humanitarian system more inclusive, and strengthening related leadership.

Other dynamics which are thought to have influenced a wider uptake of inclusion of persons with disabilities in humanitarian programming in the Syrian humanitarian response:

- Over the last five years, a number of UN and donor agencies have engaged different resources to support inclusion in its programs⁹.
- HI too had other projects supporting capacity development of humanitarian actors in different sectors to uptake disability inclusion in their respective programming, namely Health, COVID19 response, Livelihoods and Protection.

⁸ Using the WG Set of questions allows to establish a prevalence, to identify persons with disabilities and determine their access to humanitarian service levels as part of the overall affected population, through disaggregation of data. For more information on findings of the Research, see https://humanity-inclusion.org.uk/en/disability-data-in-humanitarian-action

⁹ Via action around the Guidance to support HRPs to become more inclusive, commitment to implement the UN DIS and so on.

- The Syria Resilience Consortium (SRC), operational over the past 4 years, supported a Gender, Disability and Age based approach to reinforce Livelihoods which has promoted a better understanding of the intersections affecting the vulnerability and resilience capacities of the crisis affected population¹⁰. This understanding has been shared in the form of studies with the wider humanitarian community.
- A ground-breaking empowerment project for Syrians with disabilities to raise their voices in the humanitarian response has been effective since more than a year.

The Syria humanitarian context where dedicated technical assistance has been provided to support disability inclusion in the response has been somewhat unique. However, in the case of other crosscutting themes and/or approaches such as gender, Prevention of sexual exploitation and abuse (PSEA), Accountability to Affected Persons, Principled Protection and protection mainstreaming, systematic efforts have been made to promote improvements at the country level in these different areas, supported by the global programs GenCap¹¹, ProCap¹² or NorCap¹³. These demand-driven mechanisms are based on an initial request by the Humanitarian Country Teams or UN Agency. Dedicated senior technical advisors on gender or protection have been deployed to address interagency capacity needs with the object to enhance leadership and/or capacities in humanitarian operations at field level. Evaluations of those have demonstrated the impact, i.e. change at system level, stronger leadership and accountability.¹⁴

The effects and likely impact of providing dedicated human resources to support disability inclusion at the humanitarian system level has not been studied as such in any crisis. The technical support provided to teams responding to the Syria response over the past 2- 3 years provides an excellent basis for a case study. This learning is even more needed to help planning for the operationalization of the IASC Guideline on the Inclusion of Persons with Disabilities in Humanitarian Action. Progress towards implementing this guidance is even more needed considering that in Syria 25% of the overall population, and 36% among internally displaced Syrians and 41% among internally displaced women are persons with disabilities (HNAP 2020), far more than the global average of 15% (WHO, World Bank 2011).

Objectives

The objective of a case study on the Syrian Response is required to document and better understand the inputs, outcomes and likely impacts of a dedicated human resources that have been invested to promote disability inclusion within the humanitarian system in the Syrian response, with a focus on North East and North West Syria.

This case study will aim to collect information and insight to allow for evidence-based planning of similar deployments of disability inclusion experts at the humanitarian system level in other countries as well as enrich reflections on options for provision of technical support on disability inclusive humanitarian action, taking place within Reference Group on Inclusion of Persons with Disabilities in Humanitarian Action.

Case Study – Investigative Questions:

Given that (a) this is one of the few humanitarian responses with a deployment of a dedicated field specialist on inclusion, (b) the Reference Group on Inclusion of Persons with Disabilities in

¹⁰ Such as SRC: <u>Hidden, overlooked and at risk. The role of gender, age and disability in Syria. 2019</u>

¹¹ GenCap (https://www.humanitarianresponse.info/en/coordination/gencap)

¹² ProCap (https://www.humanitarianresponse.info/en/coordination/procap)

¹³ NORCAP (https://www.nrc.no/expert-deployment/aboutnorcap/)

¹⁴ See review of the Protection Capacity and Gender Capacity Project. Evaluative Review from 2019.

Humanitarian Action is working on strengthening operationalization of the IASC Guideline on Disability and that (c) other country programs of HI and other actors have struggled to have such traction, its urgent to undertake a case study on the deployment of the Field Specialist on Inclusion. It is to investigate the following questions around effectiveness and relevance:

- 1) What impacts and/or outcomes¹⁵ were achieved at the level of the <u>Humanitarian</u> <u>System</u> (e.g. Inter cluster/ sector coordination systems, humanitarian leadership, clusters: WASH, Protection; HNAP Data Collection and reporting), its mechanisms of coordination, capacity development and its annual HPC (incl. Pool Funds), policies and guidance documents in North East Syria (NES) and North West Syria (NWS) whenever applicable to Whole of Syria (WoS) approach, in relation to:
 - a. What was the effect of more available and better use of disability data?
 - b. What was the contribution of the technical assistance provided towards the more meaningful participation of persons with disabilities and the empowerment of Organizations of Persons with Disabilities (OPDs),?
 - c. What specific interventions contributed towards the capacity development of mainstream humanitarian actors?
 - d. How did the intervention contribute towards the removal of barriers that limited the participation of persons with disabilities?
 - e. What were the observable required steps (e.g. training, technical support etc.) that led to outcomes, and perhaps sustainability and/or impact, and what were the challenges?
 - f. What types of inputs (dedicated time, support from HCT & Protection Cluster Leads, expertise, leadership in working groups or similar) and factors (e.g. humanitarian leadership, dedicated budget, existence of a mechanism to ensure inter-cluster engagement) required to achieve the outcomes and/or impact? and
 - g. What is the likelihood that the progress achieved will be maintained and sustained in the future? And what would be required to support that?
- 2) What, if any were impacts and/or outcomes observed on the level of <u>humanitarian</u> <u>programmers and programming</u>, that is cluster members, including OPDs and coordinators in NES and NWS, in relation to:
 - a. Availability and use of disability data; meaningful participation of persons with disabilities; empowerment of (Organizations of) Persons with disabilities; capacity development of Humanitarian Actors; and the removal of barriers?
 - b. Observable required steps and factors that led to outcomes, and impact, and what were challenges?
 - c. Type of inputs (facilitator, training, focal points, coordination & follow-up, etc.) required to achieve the outcomes and/or impact, and
 - d. Likeliness of achieved outcomes to be maintained in the future? And what would be required to support that?
- 3) What was learned about the deployment of the Field Specialist on Inclusion that could further inform the design, mandate or resources required for future deployments? Consider:
 - a. The Terms of Reference of the Field Specialist, looking at recommendations about what to include or exclude in future deployments;

25

¹⁵ Such as Strategic integration of disability inclusion in Humanitarian interagency Coordination or cluster level strategies or policies, HNOs & HRPs, Funding allocations, Meaningful participation of affected population in decision taking, etc.; (including a timeline of achievements over the annual HPC cycle)

- b. Placement and integration relative to the HCT, Cluster Lead Agencies and Clusters teams;
- c. Contributing factors in the humanitarian context that facilitated the deployment (or the reverse, the factors that impeded the success); and
- d. Success criteria.

Suggested Methodology

To explore above questions through participatory qualitative methods a consultant with relevant experience will undertake the following:

- A Desk Review of policies and programming tools in relation to Data Collection & Humanitarian Monitoring, Coordination, Annual Plans, selective programming documents and ToRs of Cluster,
- FGDs as applicable with representatives of the cluster and/or cluster members,
- Key Informant Interviews with humanitarian actors, representatives from affected population with disabilities, incl. Cluster leads, HCT, OCHA & UNHCR representatives, representatives of Donors engaged in Donor Coordination mechanisms, Cluster Members from local and international levels
- Facilitation of consultations with humanitarian actors to draw recommendations from initial findings.

The interviews and focus group discussions are expected to be done using online communication.

This being a participatory and qualitative approach, the consultant is expected to collaborate further with HI team to finetune objective and engage key actors to review the directives of the case study, as it is hoped to inform further programming and decision making of various actors.

Confidentiality

Given security considerations and political sensitivity in Syria, and related areas of control for implementing agencies, the case study will work with a strict anonymized approach with regards to participating agencies and participants in interviews. The findings will be used internally and shared with key participants, but not made available for the public domain.

Duration

A total of maximum three months overall duration for preparation of tools, planning and facilitation, with an estimated 10- 15 working days.

Qualification

An expert consultant with knowledge and experience of more than 10 years in the actual working of the humanitarian systems at country and global levels, capacity development dynamics in humanitarian action, Disability data and mainstreaming disability (or Gender, protection of added value) in humanitarian systems and programming, including coordination. He/she needs to show a high level of confidentiality, communication capacity and familiarity with a wide range of actors from affected population, to programmers, implementers, Data & Information experts, and coordinators.

Deliverables

- Brief report with findings
- Power point presentation

Annex 2: Worth Reading

and analyses", February 2021.

CBM, HI and IDA. "Case Studies Collection 2019: Inclusion of persons with disabilities in humanitarian action", 2019.

(http://www.internationaldisabilityalliance.org/sites/default/files/case studies inclusion of persons with disabilities in humanitarian action cbm hi ida 0.pdf)

Andy Featherstone and Tasneem Mowjee, "Independent review of the Four Priority Underfunded Areas for the Central Emergency Response Fund (CERF)", October 2020.

(https://cerf.un.org/sites/default/files/resources/CERF%20Priority%20Areas%20Review%20 Final%20Report%20201010.pdf)

HelpAge International and Handicap International, "Hidden victims of the Syrian crisis: disabled, injured and older refugees", 2014. (https://www.researchgate.net/profile/Thomas-Calvot/publication/262559526 Hidden victims of the Syrian crisis disabled injured and older refugees/links/0deec537f708417cdc000000/Hidden-victims-of-the-Syrian-crisis-disabled-injured-and-older-refugees.pdf)

Humanitarian Needs Assessment Program, "Disability: Prevalence and Impact, A Nationwide
Household Survey Using Washington Group Methodology", 2021.
(https://www.globalprotectioncluster.org/wp-content/uploads/Disability_Prevalence-and-
Impact_FINAL-2.pdf)
, "Disability in Syria: Investigation on the Intersectional Impacts of Gender, Age and a Decade of Conflict on Persons with Disabilities", 2021
, "Spring 2020 Report Series: Disability Overview", 2020. (https://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/asses
sments/syria disability overview - hnap spring 2020 report series-1 final.pdf)
, "Summer 2020 Report Series: Disability Overview", 2020. (https://reliefweb.int/sites/reliefweb.int/files/resources/Syria%20Disability%20Overview%20-%20HNAP%20SUMMER%202020%20REPORT%20SERIES-1.pdf)
, "IDP Insight: Disability", 2019.
(https://www.humanitarianresponse.info/sites/www.humanitarianresponse.info/files/assessments/idp insight - disability - idp thematic report no 5.pdf)
, "Syria Demographic Household Survey Thematic Report - Health & Disability", June 2018
Humanitarian Outcomes, "Independent Review of CERF Allocations to Syrian Conflict and Regional Refugee Crisis 2013-2015", February 2016. (http://www.unocha.org/cerf/reportsevaluations/evaluations/country-reviews/performance-and-accountability-framework)
Inclusion Technical Working Group, "Piloting Inclusive Approaches in the Humanitarian Project Cycle
Management: Concept Note", June 2021
, "Inclusion TWG Pilot project annexes (tools)", May 2021
, "The definition of disability and disability related data collection

