

















Disability

## Disability Inclusion Case Study Series: Preface and Acknowledgements

#### **Preface**

In 2019, the Inter-Agency Standing Committee (IASC) released the *IASC Guidelines* on *Inclusion of Persons with Disabilities in Humanitarian Action*, setting out essential actions that humanitarian actors must take to effectively identify and respond to the needs and rights of persons with disabilities. Shortly after the launch of these Guidelines, the global Reference Group on Inclusion of Persons with disabilities in humanitarian action was launched (the Disability Reference Group or DRG). Members of the DRG Working Group 1 (DRG WG 1) collaborated to promote and support the operationalisation and implementation of the IASC Guidelines. Over the last few years, they have received multiple requests and expressions of interest from practitioners to facilitate a deep dive into examples from the field of good and promising practices around the implementation of the IASC Guidelines on disability inclusion.

This case study series is the answer to these requests and expressions of interest to provide in-depth exploration for humanitarian practitioners seeking to be more disability inclusive in their work by sharing the stories of what this work can be like in the field. This series aims to address the lack of detailed examination of successful projects and the results they achieved through an analysis of their experiences, reflections, and the lessons they learned about disability inclusion.

Funding for the development of the case study series comes from a two-year project 'From Guidelines to Action: Promoting Learning, Localisation and Adaptation of the IASC Guidelines on Inclusion of Persons with disabilities in humanitarian action'. The project is financed by ECHO, the Center for Disaster Philanthropy (CDP) and implemented by Humanity & Inclusion/Handicap International.

#### Selection of good and promising practices

In 2023, the DRG WG1 launched a call for good and promising practices on 'what works' for transforming existing humanitarian programming into disability-inclusive humanitarian programming with the aim of fostering learning between humanitarian agencies, funded by CDP. A technical review committee (TRC), comprised of humanitarian practitioners working towards disability inclusive programming, all members of the DRG WG 1, was established to design and support the selection process.

The call for case studies was launched early 2023. Case studies were selected for focussing on various priority thematic areas that reflected the "must do" actions for

disability inclusive programming of the IASC Guidelines on Disability Inclusion. These thematic areas were identified as essential for disability-inclusive coordination efforts and programming across all humanitarian sectors to support meaningful participation and equitable access to humanitarian assistance and protection for people with disabilities. The thematic areas were:

- Empowerment of persons with disabilities,
- Capacity development of humanitarian actors, including organisations of persons with disabilities (OPDs),
- Identification and removal of barriers,
- Meaningful participation of persons with disabilities, and
- Quality disability data collection and disaggregation.

Of 41 initial submissions, 21 organisations were selected based on agreed criteria¹ and invited by the TRC members to participate in two laboratory-style peer review and learning workshops, with 19 organisations participating. The goals of these two workshop were not only to identify good practices of disability inclusion, but also to foster learning between humanitarian agencies as they each shared their projects. The TRC established a jury for the final selection² by inviting seven experts on inclusive humanitarian action from academia, think-tanks, Organisations of Persons with Disabilities, humanitarian agencies as well as the DRG co-chair. During the workshops each submission was scored by the jury members and other workshop participants as well as being documented and illustrated as briefs in a workshop report. The top 3 scoring good practices were then selected for developing the more detailed case studies in this series.

- 1. (A) Completeness, (B) Humanitarian Action Focus, (C1) Impact, (C2) Sustainability, (C3) Replicability, (C4) Relevance to the objective of the call, (C5) Innovation, (D) Compliance with the thematic areas
- **2.** Final selection criteria used by the jury were: Innovation & learning potential, Demonstrated impact, Scalability and/or replicability potential, and an additional score around cross-disability and diversity among persons with disabilities.

#### Methods for case study development

To ensure the case studies provided sufficient detail and depth for practitioners, the research methods for all three case studies comprised of reviewing key program materials and other background and published documents, as well as multiple and phased key informant interviews (KIIs) and focus group discussions (FGDs) with stakeholders involved in each project.

Adopting ethical storytelling principles to ensure the process was respectful and empowering for contributors, a series of validation workshops provided opportunities for reflection, analysis, and feedback. Organisations worked with the author to provide concrete guidance on disability inclusion in humanitarian action, including updated indicators and tools where possible.

Each case study is available in written and online, interactive versions. The online versions have been designed to support learning and development and include audio/visual clips and reflections from those involved in each project.

#### Objectives and key themes emerging

The objectives of the case study series are to provide detailed descriptions not only of <u>what</u> was done in each project, but <u>how</u> and <u>why</u>, as well as exploring the challenges and lessons learned about disability inclusion in humanitarian contexts.

This will allow users of the case study to gain guidance on the different aspects and methods for disability inclusion, based on ongoing or recently concluded projects. It also means that users will have enough detail to adapt or modify specific elements of each project to suit their own needs, including opportunities to enhance capacity to meaningfully engage with, and include persons with disabilities in humanitarian responses.

This table presents a summary of the 3 case studies that were produced as part of this project:

No.	Case study	Location	Organisations	Key themes
1	Vocational training and meaningful employment for women in the West Bank: An intersectional and transformative approach to disability inclusion	West Bank and Jerusalem	LWF-Jerusalem and CWLR	<ul> <li>Intersectionality and disability inclusion for women with and without disabilities</li> <li>Transformative changes through programming that addresses barriers and creates enablers</li> <li>Developing data collection and analysis tools to ultimately improve pathways to meaningful employment</li> <li>Encouraging self-confidence and allyship through role models and experiential learning</li> </ul>
2	No longer hidden: Inclusion Ambassadors in North East Syria — A localised approach to disability inclusion	North East Syria	Humanity & Inclusion Syria	<ul> <li>Meaningful participation of persons with disabilities as a first step towards localisation and empowerment to lead</li> <li>Supporting persons with disabilities to organise and engage in collective action to improve disability inclusion</li> <li>Collaborative approaches to capacity strengthening, including co-designing with people with disabilities</li> <li>Changing attitudes through local leadership provided by people with disabilities and the support needed to achieve this</li> </ul>
3	Ahlan Simsim and empowerment through representation: Mainstreaming disability inclusion in early childhood development for crisis-affected children in the Middle East	Iraq, Jordan, Lebanon, Syria	International Rescue Committee and Sesame Workshop	<ul> <li>Authentic representation of people (and children) with disabilities and its power to transform attitudes and behaviours</li> <li>Mainstreaming disability inclusion in mass media and direct services for crisis-affected young children and their caregivers</li> <li>Supporting disability inclusion through varied peer-based approaches to capacity strengthening and confronting stereotypes and misconceptions</li> <li>Empowering those working with children and caregivers to promote and practice disability inclusion</li> </ul>

Disability in humanitarian contexts is often described as a "hidden crisis". And each organisation in these case studies experienced challenges reaching people with disabilities, whether there were established organisations for persons with disabilities in their operational context or not.

Therefore, one of the common threads through these case studies illuminates the need for deliberate and sustained action to ensure programmes and responses are disability inclusive. It is often not enough to subsume disability under a broad banner of inclusion; dedicated staff and resources may be needed to reach and work meaningfully with people with disabilities to identify barriers and create enablers to their participation in humanitarian action and beyond. Moreover, these case studies show us that for staff and partners, we need to provide guidance and support through concrete actions they can take to be more disability inclusive.

The other major theme that emerges from these case studies is the power of representation and meaningful participation. Whether through muppets, ambassadors, advisory committees, or other approaches, ensuring people with disabilities are at the forefront as colleagues, or sharing their lived experiences, needs, and capacities is crucial to disability inclusion efforts. As humanitarians, we must make all efforts to provide the support and space for people with disabilities to engage as humanitarian actors and represent themselves and to ensure they share their stories in ways that authentically reflect who they are.

By telling the stories of each organisation's process (and adaptation) to design a program that reaches and includes people with disabilities in today's humanitarian contexts, it is hoped that practitioners will be inspired to follow in their footsteps, learn from their missteps, and ultimately take definitive action to ensure disability inclusion is an operational reality, and not only a principled goal.

Taken together, it is also hoped that the lessons learned in these case studies will contribute to a growing body of knowledge and analysis on the varied but concrete ways that disability inclusion in humanitarian action can be strengthened and improved now and into the future.

#### **Acknowledgements**

Research, interviews, and Material written by: Samantha Newman (lead consultant)

• Project management from HI and DRG WG 1 Co-leads: Charles Lunn (Humanity & Inclusion, HI), Ulrike Last (HI) & Pauline Thivillier (International Rescue Committee, IRC)

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- Canadian Lutheran World Relief
- Humanity & Inclusion/Handicap International
- International Rescue Committee
- Lutheran World Federation-Jerusalem

The DRG extends its deep gratitude to the staff of these organisations, as well as partners and affected populations who contributed so generously to these case studies. Their dedicated efforts, and honest reflections and insights, will inspire and help us all to be more disability inclusive in our work.

While these contributions have been essential to the development of this series, the content of the case studies is the sole responsibility of the DRG.

This case study series was produced with the financial assistance of Center for Disaster Philanthropy (CDP) and ECHO through Humanity & Inclusion's 'From Guidelines to Action: Promoting Learning, Localisation and Adaptation of the IASC Guidelines on Inclusion of Persons with disabilities in humanitarian action' project.

Where photographs included in these case studies were provided by the organisations, they were taken with the permission of subjects and, in the case of children, with the permission of their caregivers if appropriate. Individuals depicted in any photos should not be attributed with quotations or facts presented in the case study.

For feedback, suggestions or more information, please contact: ws1@disabilityreferencegroup.org











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"When we used to walk in pairs, they looked down on us. But now we walk with 22 people together, as if we were one person." (Woman Inclusion Ambassador)



#### **Executive Summary**

As humanitarian practitioners, many of us have witnessed the power of representation and inclusion in contexts in which we work. Not only in transforming our own responses, but in transforming the community and wider society. Supporting persons with disabilities to be partners in leading the way for greater disability inclusion in humanitarian action is not complex, but it does require consistent, and often longer-term efforts.

In North East Syria (NES), where this case study takes place, people with disabilities face enormous barriers to any kind of socio-economic and political participation. A highly culturally and religiously diverse area, NES has been subject to conflict and governance control from multiple national and international actors. People with disabilities have not only had to contend with negative stereotypes and a perceived need for them to be hidden from their communities, but also an environment where conflict has destroyed infrastructure and decimated essential services and civil society. Inaccessible buildings and infrastructure, and limited education and employment opportunities are daily realities most face – despite their ever-growing numbers.

Humanity & Inclusion (HI), like all humanitarian actors in contexts like these, faced a huge challenge – how could they support people with disabilities to meaningfully participate in humanitarian action and advocate and receive the support they desperately needed, when almost none of the disability community were known to the sector as a whole?

Over the course of two years, HI worked to change this – by working closely with an initial group of 22 men and women from NES living with diverse disabilities to become disability 'Inclusion Ambassadors' (IAs). They were called 'Ambassadors' to reflect the representational and promotional aspects of their anticipated roles in their communities and beyond, to achieve greater disability inclusion. This work was supported with funding by several donors over the course of four years, including Global Affairs Canada, a multidonor fund (with SIDA, DANIDA, and NMFA) and ECHO.

This case study will explore the ways in which HI worked with the Inclusion Ambassadors to support the work the Ambassadors went on to do to improve disability inclusion within their communities and in humanitarian action in NES, at all levels. Beginning with initial workshops, surveys, consultation and analysis, the HI team identified and then worked with 22 Inclusion Ambassadors (IAs), local men and women with disabilities, to strengthen their skills and confidence in organising, advocating, and collaborating with key stakeholders in NES (including humanitarian) to address some of the major barriers to inclusion people with disability face in NES.

Neither the project, nor the Ambassadors stopped there. The case study will explain the ways the HI team and IAs collaborated to chart the various pathways towards greater inclusion, while also identifying their own goals and activities to support their achievement. This includes how knowledge and skills were strengthened for the Ambassadors to enable meaningful participation, the work Ambassadors did within their local communities, and the work they did within the humanitarian sector to advocate for and meaningfully engage in efforts to increase disability inclusion.

Two and a half years later, the program has seen remarkable results. Public campaigning and educating local communities (including through local radio and television appearances) has seen greater awareness of the barriers people with disability face, the solutions for greater inclusion, and the crucial leadership roles persons with disability can play in bringing about changes. Through activities aimed at improving access to livelihoods, more people with disabilities have been able to access employment oppor-

tunities, including Ambassadors starting small businesses. To provide greater access to public services, Ambassadors worked with authorities to create a 'disability card'.

And to improve public infrastructure accessibility for persons with disabilities, Ambassadors worked with authorities to create new legal requirements for new buildings and allocation of local government funds to support disability inclusion measures.



Most recently, and crucially, it has resulted in the creation of the only Organisation of Persons with Disabilities (OPD) in NES: the Ambassador's Association for Persons with Disabilities has been established by the Ambassadors to: advocate for the rights of people with disabilities in Syria to participate fully and effectively in society, on an equal basis to persons without disabilities.

Ambassadors have also worked increasingly closely with humanitarian actors to support their organisations to be more disability inclusive. The case study will illustrate examples of the approaches they have used, with HI's support, including workshops, coaching, advising, and supporting humanitarian actors to devise disability inclusion action plans and pilot disability inclusive planning, monitoring, and data collection tools.

How these Ambassadors were empowered to achieve the remarkable results they have accomplished in a relatively short amount of time is a testament to their courage, commitment, and diligence. It is also a powerful demonstration of what can be achieved with a localised approach to disability inclusion. This case study will explore how HI, in partnership with persons with disabilities, were able to go from almost no engagement with the wider humanitarian sector to the regular collaboration seen today. More, it will show you the transformative possibilities that empowerment and collective action can bring for individual men and women facing discrimination, limited education, and understandable self-doubt for some, to publicly advocating for their rights to inclusion and participation with senior decision-makers, international donors, and even in the media (through radio, television etc).

This case study illustrates how capacity strengthening, done well, is integral to meaningful participation and can lead to empowerment and eventual localisation for persons with disabilities – not only to participate but to lead in humanitarian action. Building on the IASC *Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action*, the work HI has done here takes disability inclusion a step further – showing us the impacts a localised approach can achieve, leading to long-term improvements not only for the humanitarian sector, but for the individual lives of people with disabilities and the wider community they live in. It challenges us as humanitarian practitioners to be willing to be led by people with disabilities who, when given the opportunity, can chart the most effective ways to remove the barriers they experience every day.

Perhaps most of all, this case study demonstrates the power of collective action for people with disabilities. When supported to organise and develop community-based groups, people with disabilities are empowered to speak with collective voices on ways their communities, and the organisations that support their communities, can take action to ensure people with disabilities in NES have the same opportunities to live meaningful, purposeful, and dignified lives.



#### Introduction

Syria has been experiencing over a decade of conflict and crisis. Hundreds of thousands have been killed in the conflict and it has the world's largest number of people displaced and almost 70% of people in Syria require humanitarian assistance. The devastating earthquake in early 2023 has only made this dire situation worse for nearly 9 million people.

North Eastern Syria, where this story takes place, is an area where different ethnic groups live side-by-side – including Kurdish, Arab, and Assyrian populations, as well as ethnic Turkmen, Armenians, Circassians, and Yazidis. Since 2011, the area has been subject to changing governance and control involving both domestic and international state and non-state actors. This has given rise to conflict and waves of humanitarian crises.

One of the largest and most hidden crises relates to people living with a disability. While exact numbers of people with disabilities are difficult to obtain, a 2023 report based on data collected on people with disabilities in Northern Syria found that 52% of the population over two years of age had some kind of disability or difficulties in performing daily tasks<sup>1</sup>. This is over three times the global average and makes Syria one of the most difficult places in the world if you have a disability.

**1.** Assistance Coordination Unit, *Disability in Northern Syria – Prevalence and Impact*, Edition 01 October 2023, available at: https://reliefweb.int/report/syrian-arab-republic/disability-northern-syria-prevalence-and-impact-october-2023-enar

Despite these high rates of disability amongst the population, there is a severe shortage of essential and support services available for people living with disabilities. And access to essential services and care, particularly for those with injuries, disabilities, and chronic illness is extremely difficult, compounded by damage to local infrastructure and restrictions on movement. The impact on communities has been profound, made worse by a decimation of local civil society and community-based organisations. At a local level, until very recently, no one was advocating or promoting for the rights of people with disabilities to be included in community life and in humanitarian responses.

Cultural attitudes and misunderstandings within communities as to the rights and capacities of persons with disabilities also contribute to the hidden nature of this crisis and the exclusion they experience every day. For some families, a sense of shame and embarrassment at having a family member with a disability prompts them to literally hide that person from the outside world. For some women, these attitudes intersect with traditional gender norms, excluding them from work, decision-making, and community life in general. Persons with disabilities in NES reported to Humanity & Inclusion (HI) that they had experienced regular and ongoing discrimination, misunderstanding, and exclusion in all areas and ages of their lives – in schools, in employment opportunities, in accessing basic services and support. Many people with disabilities do not feel they are able to meaningfully participate in their communities or within their families, including decisions affecting them, or have access to the same opportunities that people without disabilities have.

These cultural attitudes and difficult economic circumstances have meant many children with disabilities were excluded from accessing educational opportunities after around eleven or twelve years of age. Discrimination and bullying by staff and students, or doubts or fears within their families, often based on myths and stereotypes, meant that many missed out on the education afforded to their peers. A vivid example of this was discovered by HI at an event held where the team discovered that participants with hearing impairments used their own individualised form of sign language, such that they could not communicate with each other or the sign language translator.

The severe socio-economic impacts of this context on people with disabilities, their families, and carers, are easy to see. Unemployment rates are much higher for people with disabilities, adding financial strain to people already living in a financially precarious situation. The lack of recognition or inclusion people with disabilities face means they are often almost entirely socially excluded from their communities. This has a compounding effect on their psychosocial wellbeing and further entrenches their exclusion and hiddenness.

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"...We are in a society that considers a person with a disability less than a human. And in war, some think that leaving people with disabilities behind to die is a natural thing. I have witnessed that with my own eyes." Inclusion Ambassador, F

"I used to go to school crawling; put my bag on my back and crawl. I suffered a lot from bullying; my schoolmates made fun of me, they used to jump on my back." Inclusion Ambassador, M

"The financial situation at home was bad. My father was married to three women and I was the youngest girl. According to customs and traditions, he did not accept me undergoing any operation." Inclusion Ambassador, F Humanity & Inclusion has been operational within Syria since late 2012 and manages projects related to health, land release, and disability inclusion through direct intervention and in partnership with local partners. This includes providing assistive devices, physical rehabilitation, and psychosocial support to people with disabilities, injured people, and caregivers.

HI in NES aims to increase the accessibility and inclusion of communities for people with disabilities by raising awareness within communities and their stakeholders, through working closely with local actors to build their capacities in disability inclusion, by rehabilitating infrastructure to be more accessible for persons with disabilities, and through providing individual case management to people with disabilities. It also works with other international humanitarian actors, and within interagency collaboration and coordination bodies, to support and promote disability inclusion in humanitarian action and response.

This case study will explore the localised approach HI took to provide support for people with disabilities for them to identify barriers and enablers that would allow them to participate meaningfully in their communities and in humanitarian action, and to ultimately have access to the same support and opportunities available for people without disabilities. No longer hidden, there are now 22 'Inclusion Ambassadors' who collaborate together to determine their own priorities and implement activities to achieve their own objectives, with continued support from HI.

"My father was a teacher, and when I went with him to school, the principal refused to receive me, saying: 'I do not accept a person with a disability to come to study here." Inclusion Ambassador, F

"I was an employee in an organisation and my rights were violated. But I never said anything, and many times I used to say to myself: 'At least they hired me."

"The mosques are open to everybody, as they are the houses of God. But they do not understand the needs of people with disabilities at the entrance."

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"I suffered from displacement a lot. At the time of my displacement, I was still using crutches. Two months later, my leg was amputated."



## The Challenge: How can we support people with disabilities to meaningfully participate in their communities and in humanitarian action?

In early 2019, HI faced a dilemma – how could they improve disability inclusion in communities and in humanitarian action in NES? There were no organisations for persons with disabilities (OPDs) in existence and, due to the lack of visibility of many people with disabilities within communities throughout NES, HI had not been able to establish significant links with them. There was no 'disability community' within NES at the time. As such, people with disabilities had no interaction or involvement with humanitarian organisations and responses, and therefore no knowledge or understanding of the way the humanitarian system operated, nor how they could meaningfully engage with it to encourage and support disability inclusion.

This meant the first step for the HI team was to address their own knowledge gaps – to reach out and begin conversations with people with disabilities and to listen to what they had to say. They did this in two ways: by conducting a workshop at the end of 2019 and following this up with an extensive community mapping exercise in the early months of 2020. For the initial workshop held in 2019, participants and carers were identified through various government and non-government organisations, ensuring

diversity of age, gender, and disability. The workshop provided a space for people with disabilities to discuss and share the various barriers they faced to participating within their communities and to brainstorm on potential solutions. It was through this discussion that HI learned how significant the barriers were in NES in terms of accessing employment, education, and essential support services. Following the workshop, it was clear to HI staff that they needed to learn more and reach out to more people with disabilities and their families, particularly those unknown to services and organisations - those more hidden from their communities and more vulnerable as a result. This prompted a follow-up community mapping activity that was conducted in the early months of 2020. Using surveys, key informant interviews and focus group discussions, HI were able to reach 701 people living with a disability and their primary caregivers and 640 households with more than one family member living with a disability. The mapping exercise revealed that while there were a few service-based organisations that were supporting people with very specific disabilities, there were no communitybased organisations (such as OPDs) that were engaged in advocating for laws and policies that would support disability inclusion.

Drawing from the data they collected, and conversations they had with people with disabilities in NES, HI had a much clearer idea of the barriers they face which limit their access to and inclusion in their communities and societies. These included:



**Attitudinal barriers:** These are individual, familial, and community-held negative attitudes and beliefs, influenced by cultural, religious, and gendered norms that have exclusionary and discriminatory effects on people with disabilities and their capacity to participate in everyday life.



Environmental barriers: There are widespread environmental barriers in NES. None of the built environment has accessible infrastructure, transportation, and movement (difficult for many without disabilities) are severely restricted, and a lack of services (and access to existing ones) create significant restrictions on opportunities for people with disabilities to participate fully in their communities.



**Institutional barriers:** Until recently, there were no specific laws, policies, or strategies to encourage inclusion or address the causes of exclusion and discrimination.

The seeds of the idea for creating an "Inclusion Ambassador" program emerged from the discussions between HI staff and people with disabilities held during this initial workshop. The term 'Ambassadors' was selected to reflect the representational and promotional aspects of their anticipated roles in their communities and beyond, to achieve greater disability inclusion.

These discussions and the subsequent mapping conducted revealed that encouraging and supporting disability inclusion through the meaningful participation of people with disabilities in their communities and in humanitarian action needed to begin from the ground up. This meant HI needed to work with them to provide the foundations of knowledge and skills that would enable this participation, as well as the support needed to build informal local groups of Ambassadors so they could organise and work together for the changes they wanted to see.

"I always dreamt about going to school and continue my education, but I couldn't find the proper support from the principal of the school I wanted to attend, and no one from my community or family supported me to continue my education. And now I suffer a lot while teaching my children because I always [need to ask] for support from my neighbors and close relatives, because I am not educated enough to teach them. On the other hand, sometimes I learn with them through their classes and subjects, despite my disability, as I have discovered that I have a great ability to learn." (Mother of two with vision loss)

"I never considered myself as a person with disability, as I normally can do all my daily activities independently. However, the sidewalk is my disability, the stairs in my school were my disability.

The (environmental, institutional and social) barriers around me caused my disability not my physical impairment. But I had a great support system from my family from my friends and even from my Principal at school who was a great enabler for me to continue and fight for my education."

(Woman with physical disability)



## The Opportunity: Building a cohort of local Disability Inclusion Ambassadors

Supporting the development of a cohort of people with disabilities able to advocate for and advise on disability inclusion to local communities and the humanitarian community from the ground up was not going to be easy or swift. In fact, the HI team believed the best way to build capacity, confidence, and create opportunities for disability inclusion and meaningful participation was to deliberately take it slowly and in a staged manner.

Therefore, the project's aim was to reduce existing barriers and help to enable people with disabilities to participate more equitably in society. Specifically, to help people with disabilities to develop the skills and confidence to be able to advocate and organise to work with local communities and the humanitarian actors working in their communities on how to not only **meet their needs**, but to also **collaborate with them to make everyday life more accessible** for people living with disabilities.

#### The goals of the project were:

- To help persons with disabilities to understand their rights within their communities in a concrete way
- To support persons with disabilities to have the skills and confidence to advocate for the realisation of these rights within their local communities – including with humanitarian organisations operating in their areas
- To support persons with disabilities to create informal local networks to collaborate and improve disability inclusion within their community and to provide a supportive environment for each other

 To strengthen the capacity of HI staff and its partners to support persons with disabilities develop necessary skills and support them to organise and manage their informal local networks

#### To achieve these goals, the program took a twopronged approach over two years:



**Inclusion Ambassadors**: These would be a group of 22 people with disabilities who, over the course of a year, would build their skills and knowledge, and then co-design awareness-raising and training activities which they would then facilitate within their communities (to community members, community-based organisations, and humanitarian organisations).



**Informal local peer support groups**<sup>2</sup>: In the second year, Ambassadors would work in small informal groups in four different localities (called "self-help groups"), supported by HI, to identify the priority areas and activities they wanted to work on and start to implement them. This would also provide a space for peer support and reduce social isolation for people with disabilities.

The local, community-based solutions for the challenges and barriers described in the previous section were identified by people with disabilities while working with HI and within their informal local groups. Through regular meeting and brainstorming, members of each local, informal group collaborated to identify the areas they thought required prioritisation in their community and the actions they could take to bring about solutions and greater disability inclusion. Examples of these activities are described in the next section.

#### Creating the first Inclusion Ambassador group

To select Ambassadors, the HI team used the following criteria (where possible):

- Diverse in types of disabilities
- Gender equality
- Diverse age range with representatives from all age groups
- Those currently working and those unemployed
- Those with fairly recent education and those without
- A percentage of persons with disabilities who are not involved in their community at all
- Diversity of persons with disabilities from each localities/sub-region
- Diversity of movement-related status (e.g., residents, returnees, internally displaced persons)

In addition to these diversity considerations, Ambassadors were selected through a process of discussions with each person, not only at the beginning of the program, but throughout to ensure each person with a disability was making a decision to continue with the program freely and was feeling sufficiently supported.

2. Self-help groups are used in various forms in the disability sector. In addition to being an organisational tool for collective action by persons with disabilities for persons with disabilities (e.g., engaging in activities related to health care, rehabilitation, education, and campaigning), they also facilitate empowerment through collective action. For more information, see: https://www.kindernothilfe.org/multimedia/KNH\_INT/KNH\_Englisch/Self+Help+Group+Approach+Manual-p-54022.pdf



#### The Process:

#### 01.

#### Meeting them where they are: strengthening capacity with Inclusion Ambassadors

When considering the process for designing capacity strengthening plans for IAs, HI ensured it aligned with **inclusion** and **localisation** principles. This meant viewing capacity strengthening as a two-way process whereby both IAs and HI staff were collaborating to learn from each other and contribute to the project's goals. It required viewing expertise and capacity in a broader and more egalitarian way and resulted in a much richer experience for both HI staff and Ambassadors.

Working with people with disabilities to identify suitable topics and areas to focus on, the initial 10-day comprehensive Inclusion Ambassador learning program ran over a month in 2020. Over the months that followed, additional capacity building activities were designed and implemented to address emerging gaps and needs identified by the Ambassadors. These were some of the main topics that were covered:

- Empowerment and disability rights (including international instruments and tools such as Convention on the Rights of Persons with Disabilities; Washington Group Questions; IASC Guidelines on the Inclusion of Persons with Disabilities in Humanitarian Action see Further Resources list at the end of this case study)
- Advocacy and advocacy action planning
- COVID-19 and disability inclusion in the COVID-19 response

- Accessibility for people with disabilities
- Gender, disability, and age issues (including gender-based violence)
- Psychosocial support (managing stress; supportive communication)
- Inclusive livelihoods and Water, Sanitation, and Hygiene
- Establishing informal local groups/networks
- Conducting community awareness-raising activities
- Coaching persons with disabilities and older persons
- Safeguarding and protection of persons with disabilities
- Disability inclusive humanitarian action 12

The HI team, again in partnership with the Inclusion Ambassadors, developed accessible learning methodologies that included scenarios and role-plays that simulated the challenges and barriers they experience in daily life. It also provided space for discussions and planning with the Ambassadors on how they would establish their small local groups, engage with their communities, and advocate to policy and decision-makers on the needs for greater disability inclusion in their localities.

Supporting disability inclusion means, as humanitarians, we need to take measures to ensure our working relationships with people with disabilities are not extractive – that is, taking their insights and ideas without compensation. As one practitioner put it: "If we want meaningful participation, we must be willing to pay for it."

Here, it meant ensuring that those participating in the IA program and conducting disability inclusion activities were not doing so as unpaid volunteers. Instead, each signed a contract with HI that allowed them to be paid for the important work they were doing in building community awareness, advocating for disability inclusion, and strengthening disability inclusion capacity with humanitarian actors. Ambassadors were also supported with additional accessibility measures such as transportation to events and equipment they may need.

#### Accessibility measures checklist:

Conduct an accessibility assessment of the venue and needs of participants

Ramps at venue access point(s)

Ramps to access toilets

Toilet frames for safe access

Quiet space

High contrast PowerPoints

Sign language translators

Staff to describe visual information

Staff to support people with learning difficulties

"... I did not know that I have rights, and thank God I learned that, and my selfconfidence has increased."

"My self-confidence increased, as the word (disabled) affected my personality, but after participating in this program, I learned about our rights as persons with disabilities and how to deal with society."

#### Informal local peer support groups: Taking action for local disability inclusion

Once IAs had completed their initial comprehensive training program, they formed four informal local groups for each of the localities/areas they lived within. These informal groups have several purposes:

- Members of each group work together to identify priority areas and activities to increase disability inclusion in their municipalities and address barriers they have experienced
- Ambassadors provide ongoing peer support to each other in their everyday lives with the challenges they face and opportunities that arise, and with the work they are doing together
- Ambassadors provide advice and support to members of their community living with disabilities as they build their profile within their localities
- Lastly, as these groups continue to grow and learn, they will be able to encourage other groups to form where needed and appropriate

The work the Ambassadors have done to bring about change and build capacity in their communities is explored in the next section.

#### Support HI provided to informal IA groups (varies according to the local context):

- Initially take on a facilitator role to help the group establish themselves, organise roles and responsibilities, and methods of meeting and communicating
- Have regular meetings to provide guidance and monitor group dynamics and cohesion
- Consider ways to build trust in the group
- Provide training, coaching, and other forms of support on different aspects of group/collective organisation and action (including skills-building) based on needs identified by the group
- Assist groups to identify priority needs and activities in their area

#### 02.

#### Change-makers: Encouraging communities to be more disability inclusive

A few months after completing their capacity building program, in early 2021, the IAs began forming their informal local groups, based on their geographical locations. As such, four groups were established who worked together to determine **what areas** they initially wanted to work on in their communities and what were some of **the methods** they could use to bring about the change they sought. Having a diversity of age, gender, and disability within each group meant that the analysis and decisions made to engage in activities would support a diversity of needs and lived experiences.

While the HI team initially thought groups would focus on livelihood opportunities for persons with disabilities, it was the Ambassadors themselves who decided what they wanted to work on; HI was there to provide support wherever it was needed.

#### As such, each group focussed on a different aspect of disability inclusion:



**Group A** decided to focus on designing and implementing a widespread campaign to educate their communities about disability and disability inclusion, using different media outlets to support communicating their messages. They worked with various local radio and TV stations on how their messages could be mainstreamed in media content and conducted several interviews where they shared their lived experiences, including confronting stereotypes and barriers they had encountered.



**Group B** focussed on improving access to livelihoods opportunities for people with disabilities. They worked with governing authorities to identify ways the labour market and local municipalities could be more disability inclusive, as well as conducting community awareness sessions with local stakeholders (and business associations/employers) on the rights of people with disabilities to work and practical steps they could take to provide pathways to employment.



**Group C** worked on advocating for changes needed to ensure public services were accessible to people with disabilities. They came up with the concept of a 'disability card' that would assist persons with disabilities to

access different essential services (e.g., fuel, gas, and food items) and persuaded authorities to take action. In less than six months, authorities began issuing these cards.



**Group D** focussed on the lack of disability accessibility in public infrastructure in their communities. They worked with local municipality authorities to develop new rules and regulations including annual budget allocations for accessible building measures and a requirement that new buildings must have disability accessible first/ground floors. The measure, Circular 48, was passed into law in 2022.

In addition to these activities, IAs conducted a series of community awareness-raising sessions where they shared their stories and lived experiences of the barriers and exclusion they have endured, educated participants on the rights of persons with disabilities to equitable and meaningful participation in community life, and discussed concrete ways the community could be more inclusive by transforming barriers to enablers. Sessions covered a range of topics, including:

- Understanding what "disability" means
- High percentages of people living with disabilities in Syria and the impacts this has on society
- Obstacles and barriers people living with disabilities face in their communities
- Rights of people with disabilities and how they can be realised in North East Syria
- Capacities of people with disabilities, including work and work opportunities

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"We contributed to changing society's view of us and changed our view of ourselves as well. All these positive results are thanks to this simple work that we have done..." HI organised and facilitated regular meetings with all the Ambassadors which allowed the small local groups to learn from each other about what was going on in each locality and brainstorm on actions and activities to support this work. It also allowed HI to learn from and be guided by Ambassadors in terms of their ongoing needs and how to support them. This included ad hoc capacity building activities, particularly those that focussed on 'soft skills' such as facilitation, consensus-building, persuasion, media engagement, and others.

HI also sought the Inclusion Ambassador's expertise and advice for their other humanitarian activities. For example, some worked with HI to design disability inclusive Information, Education, and Communication (IEC) community public health materials – particularly crucial during the pandemic given the vulnerability people with disabilities have to the effects of COVID-19.

Ambassadors have taken the lead in every respect, from beginning to end. This has included conducting community consultations, drafting assessments and action plans, coordinating with community members and leaders, and of course leading the events themselves. One Ambassador within each community is responsible for overseeing any remaining actions needed to improve access and inclusion to ensure momentum isn't lost within the community.

These outcomes demonstrate the power and impacts of localised approaches to disability inclusion and the personal transformation many IAs have experienced in a short period of time. Some Ambassadors joined the program having been significantly excluded from school and education, knowing nothing about disability rights or inclusion, and lacking in confidence. Yet within a year they felt empowered to share their experiences and assert their rights publicly, including in televised interviews. IAs reported gains not only in self-confidence and experience from facilitating community awareness sessions, but also increased trust and acceptance from their local communities.

"We benefited a lot from the Ambassador's program. We did not know anything about disability, or persons with disabilities, nor about our rights. We were marginalized from our society, but we were able to change this inferior [community] view of persons with disabilities after joining this project."

HI observed that the localised, community approach undertaken by the Ambassadors showed sensitivity to context, a desire to empower communities and people with disabilities, high levels of community participation and increased community acceptance, not only for people with disabilities, but also for HI and its work.

#### 03.

## Supporting humanitarian organisations to be more disability inclusive: A co-design approach to capacity strengthening

#### "By us, for us"

To encourage and support disability inclusion in humanitarian action in a manner that is consistent with the *principles of disability inclusion and localisation*, a **co-design approach** was adopted where IAs, HI staff, and partners regularly collaborated to determine which topics and themes were most relevant and necessary to cover (for everyone) and which methodologies would be appropriate to build skills for those involved in the humanitarian response in NES to be more disability inclusive.

#### What is a co-design approach?<sup>3</sup>

Co-design is an inclusive, collaborative process whereby a diverse range of people with relevant skills, experience or interests come together to provide advice and make decisions on a project, policy, program, or initiative.

Co-design is used across a range of different sectors and is not disability specific. When used in the disability sector, it is important that the co-design group includes people with a range of different experiences of disability, in addition to other aspects of diversity (such as age, gender and sexual identity, location, cultural background and language).

**3.** Purple Orange, *Guide to Co-Design with People Living with Disability*, available at: https://purpleorange.org.au/what-we-do/library-our-work/guide-co-design-people-living-disability

#### These images explain how co-design differs from consultation.



# Stakeholder Stakeholder Your organisation

As with their community outreach and local advocacy activities, within a few months of completing their capacity building program IAs were co-facilitating workshops and other events with the HI team that aimed at increasing disability inclusion in humanitarian action with local and international humanitarian organisations. These capacity building activities focussed on a range of sectors, using a variety of methodological approaches, to learn and adapt their approaches as they gained more experience.

For example, two of the first activities they were involved in focussed on supporting humanitarian responders to assess and ensure **sites and settlements** were gender, age, and disability inclusive and addressed barriers for people with disabilities. This included a variety of topics and areas from building and site accessibility needs to training participants on how to collect disaggregated data using an inclusive assessment tool Ambassadors helped to design. Another focussed on disability inclusive **water**, **sanitation and hygiene** 

**(WASH)** responses. And another worked with **protection** actors on how to identify and analyse risks for persons with disabilities and design disability inclusion plans. Driven by the experiences of exclusion, bullying, and stigmatising that many IAs experienced in their younger years, Ambassadors were eager to engage with the education sector to encourage teachers and students to be more disability inclusive. They also met with local Ministry of Education officials to discuss ways policies could be developed and support given to educational institutions and schools to remove barriers for people with disabilities and fulfill their rights to equal access to educational opportunities. Over time, HI and IAs designed a new and innovative methodology for building humanitarian responder capacities to develop measurable disability inclusion plans. These workshops continue to be run, co-facilitated with IAs. For more information on these activities, see the **Annex** at the end of this case study.

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"The Ambassador program put into words the suffering that I experienced. They put their hands on the wound."



#### Impacts & Outcomes

The Inclusion Ambassador program has continued to evolve, led by the Ambassadors and their wishes. For the Ambassadors, this has required time and ongoing support from HI as they have learned to collaborate; and learned from each other. With each new experience, whether that's been leading a community awareness-raising event, being interviewed by journalists, speaking at international donor events, or facilitating workshops with humanitarian practitioners, they confidence in their knowledge, insights, and skills has grown.

The impacts and outcomes have been numerous and cover a wide array within their communities, the humanitarian sector, and the wider NES society. Here are a few highlights:



**Humanitarian Disability Inclusion Action Plans**: Through the RAAL Labs and other activities, IAs have supported organisations to develop action plans with concrete actions and indicators to measure progress and impact.



**Legislative changes**: IAs advocated and worked with government authorities to pass *Circular 48 of 2022* which allocates funding within the annual budgets of the Autonomous Administration institutions in North and East Syria to provide facilities for people with disabilities. There are also now requirements that all new buildings must satisfy specific accessibility requirements.



Changing attitudes within communities and families: Ambassadors have reported noticing a greater willingness to engage them in discussion and listen to their perspectives within their communities. This has been particularly noticeable in families where they are much more involved in decision-making than before their involvement in the IA program.



**Inclusive public spaces**: To promote a culture of inclusion, a local garden was created to be age and disability inclusive. This involved restoration, landscaping, equitable labour practices, utilisation of colour contrast, adherence to universal design standards for ramps, and adapting seating for this people with disabilities and older people.



**Television, radio, and print media**: IAs worked with various local media outlets to encourage them to promote and practice disability inclusion. This included producing an informative video on disability inclusion for television and radio broadcast, the development of a talk show featuring interviews with people with disabilities, and a program focussing on women living with disabilities.



Participation in international events: In 2021, several IAs participated and shared their experiences as a person with a disability in NES and the activities they've been engaged in at the Brussels Conference on Supporting the future of Syria and the region and the Berlin Conference on Refugee Rights Conferences, the Conference of States Parties to the Convention on the Rights of Persons with Disabilities (in New York), and contributed to an International Day of Persons with Disabilities to share their experiences and challenges during the COVID-19 pandemic.



**Supporting entrepreneurial efforts**: Two Ambassadors decided they wanted to set up a small handicrafts business, so they raised their own funds to have some initial capital for materials and equipment. Since then, their business has grown, and they have been able to employ other women with disabilities.





### Inclusion Ambassadors establish the first OPD in NES: The "Ambassadors Association for Persons with Disabilities":

For some, the collective power the Inclusion Ambassadors built and the successes they experienced was so revelatory, they began to explore ways to create a formal community-based organisation. And so, in 2023, a group of Inclusion Ambassadors opened the doors to their new organisation – the **Ambassadors Association for Persons with Disabilities.** 

This is the first community-based non-governmental organisation, formed by people with disabilities, specifically focussed on supporting and advocating for the inclusion of persons with disabilities in NES. Its objective: to advocate for the rights of people with disabilities in Syria to participate fully and effectively in society, on an equal basis to persons without disabilities.

The work involved in bringing this about was substantial and HI were there to support Ambassadors with each step, including obtaining the required licenses and permissions from relevant authorities, finding a suitable office headquarters, and designing the procedural rules and workplans.

At present, the Association is entirely self-funded by the Ambassadors. They are formally registered in six-month increments – at the end of each six months they are required by authorities to demonstrate their progress against the goals and objectives they have set for their organisation in order to continue being registered.

#### **Current activities of the Association include:**

- Working with local authorities to improve quality and accessibility of essential services for people with disabilities
- Organising local events to raise awareness of barriers people with disabilities face and activities that can remove them
- Advocating and campaigning, including through media channels, on the rights of people with disabilities and how those rights can be realised

#### Support IAs requested from HI to help them establish and run this new OPD, included:

- 1 How to write a resume
- Creating project proposals and budgets
- How to seek and obtain funding
- How to manage human resources
- How to plan and organise logistical matters
- 6 Conducting monitoring and evaluation
- Case management skills
- B How to create training manuals
- Report writing skills
- Governance and other policies, procedures, and skills (e.g., safeguarding)
- Advocacy and messaging
- Running and facilitating meetings



## Meaningful employment: Becoming an HI Ambassador worker

Today, there are two staff working for HI as "Ambassador Workers". They are responsible for supporting the Ambassadors and the Ambassador program with their day-to-day needs. This means they are in regular and ongoing contact with the Ambassadors both in terms of the Association (OPD) and the small informal local groups that continue to operate in NES.

One of their important functions is to continue to grow and expand this network of informal ('self-help') groups throughout NES. Typically, this begins by meeting individually with a person with a disability and their families and/or carers in their homes to get to know more about them and their needs and to provide basic information on support and services available to assist them. Once trust and confidence has built with the Ambassador Workers, they can encourage them to meet with others in their locality who have shared experiences. This is the early stages of a 'self-help group'. Over time, within the group, Ambassador Workers assess levels of interest in engaging more in local activities to promote disability inclusion.

#### Friendship

For those who know and work with the Inclusion Ambassadors, it would be impossible to reflect on the impacts and outcomes of the Ambassador Program without noting the powerful impact the friendships they have formed through this program on each Ambassador. This is not to say that there haven't been the usual challenges that arise when a group of strangers from diverse backgrounds start to work together. But working together over a number of years, sharing their experiences, supporting each other through grief and loss, celebrating victories and achievements, has created close bonds between them.

"Before the Ambassador Program, I barely had the confidence to leave my home; I had so much fear and experienced a lot of bullying and criticism. I could never have imagined at that time that one day I would be working for an international NGO. But through being involved in the Ambassador Program and the capacity building I experienced, I learned I had rights, and I began to feel stronger and more courageous. Now I can easily go anywhere I want. I have confidence in myself and my family and community have much more respect for me."

"A big and radical change has affected me, and I learned that we have the right to study, learn and work, and the most beautiful thing about the project is that I met a new family, who are ambassadors and trainers."



"We became like brothers."

"As if we were searching for each other."

"We all love each other as friends in this work. As if we've known each other for a long time."

The impact that this has had on their confidence and wellbeing, and the difference this has made on their previously isolated and often lonely lives, can't be overstated. Put simply, for many Ambassadors, they have become family.

#### Where to from here? Next steps

The Ambassador program continues to support the original cohort of Ambassadors in their work, both locally, and through the Association (OPD). HI's Ambassador staff continue to work with the four informal peer support groups in their communities. And will support new local informal groups continue to emerge as people with disabilities become more visible leaders in their communities throughout NES.

Inclusion Ambassadors continue to support HI's broader work encouraging humanitarian actors and responders to adopt more disability inclusive measures and activities to support the meaningful participation of persons with disabilities in humanitarian action. This includes continuing to co-facilitate capacity building activities, supporting organisations to design disability inclusive data collection tools, and providing advice and inputs through interagency coordination mechanisms such the Syria Resilience Consortium.

Building on the community awareness-raising IAs have been doing for the last couple of years, they are working with HI to support community-based disability inclusion action planning – measurable activities to address, remove, and prevent barriers for people with disabilities at a local level. This includes priority action in communities to create accessible buildings, infrastructure, and public spaces.

Now that there is a cohort of experienced Inclusion Ambassadors, they now support new IAs as facilitators in capacity strengthening activities.

To ensure Inclusion Ambassadors can rely on their ability to continue their work, particularly through their newly established OPD, HI is supporting with capacity building activities aimed at strengthening the knowledge and skills Ambassadors have in seeking funding opportunities – including areas such as advocacy, fund raising, and proposal writing. It supports the Ambassador's Association goal of becoming completely independent as an OPD, working with the Association to define the roles and responsibilities of members, the capacity needs for fulfil these roles, and how to support members to build the necessary skills for these new roles.

## What can we learn about disability inclusion in humanitarian contexts from this story? (Lessons Learned & Key Take Aways/Guidance for Practitioners)

The concept for Inclusion Ambassadors came out of a context where conflict had destroyed civil society and there were no OPDs or alliances advocating for disability inclusion within humanitarian responses or communities. It came out of context where people with disabilities face enormous barriers to any kind of socio-economic and political participation, where they are largely hidden from society, with limited access to education and employment.

Most crucially, it came out of a context where NGOs and humanitarian actors had no engagement with people with disabilities, barring a few specific health services. In fact, 90% of persons with disabilities reported that they had dropped services because of how they were treated by humanitarian organisations. It is not surprising in this context that confidence amongst many people with disabilities was low, and underestimating their capacities was high.

This case study encourages us to examine how we, as practitioners, can work with people with disabilities to build capacities, opportunities, and mechanisms to empower them to work for greater disability inclusion, not only in humanitarian responses, but also within their local communities. And that by doing so, we are also supporting localisation and the rebuilding of civil society.



Within this context, supporting meaningful participation needed to begin from the ground up, establishing the foundational knowledge and skills to give people with disabilities the confidence to take the lead in determining what, who, and how they would engage with other stakeholders to improve disability inclusion. It began by meeting them where they were and working closely with them, step-by-step, giving them time and room as they began to explore what disability inclusion meant for them. And then it meant supporting them to implement their own plans, both individually and collectively. This included supporting people with disabilities to organise themselves such as providing meeting spaces, helping with transportation, and providing ongoing coaching and guidance through regular communication and engagement with their work.

Applying and operationalising the IASC Guidelines on disability inclusion in humanitarian action requires us to support the meaningful participation of persons with disabilities. This requires us to understand not only the barriers they face and the needs they have, but also the skills and confidence they have. Beyond the opportunities we can create for people with disabilities to engage with the humanitarian sector, what kinds of engagement do they feel ready for? While the Inclusion Ambassador training program only took a month to complete, the Ambassador program took two years to slowly build experience, applied knowledge, and the confidence these experiences brought for Ambassadors to feel ready to establish their own organisation. At this point, HI continues to provide support, but in a less intensive way.

#### Capacity strengthening as collaboration

Collaborating and building capacity with people with disabilities should be seen as a two-way process – a conversation where staff and people with disabilities have significant contributions to bring to each other. Here, while the primary function was to strengthen the capacity of IAs to feel empowered to encourage their communities and humanitarian organisations operating within them to be more disability inclusive, they also had

significant contributions to build the capacity and knowledge of staff. Most particularly, they helped train staff on how to work with people with disabilities in an accessible, relatable, and meaningful way.

As humanitarian practitioners, this requires us to take our time getting to know each individual person with a disability – their stories and experiences are essential to their own capacity building journey and what they do afterwards.

At the same time, engaging in public-facing activities can present risks in many humanitarian contexts. In addition to public health risks, there are also safety and security risks that are both inherent to conflict contexts, and potentially amplified where people with disabilities are publicly communicating messages some in their communities may strongly disagree with.

In this case, HI have a duty of care to Inclusion Ambassadors, and this has required protection analyses to be regularly conducted and strong *safeguarding* measures put in place, developed with the Ambassadors, to provide the highest possible protection for Ambassadors and to ensure they only engage in activities they felt comfortable with.

Co-design processes where persons with disabilities are involved in the design of learning and capacity development materials, as well as implementation through facilitation, requires regular assessments and ongoing work with IAs (and potential future IAs) to review, adapt and improve learning materials. This ensures materials remain relevant and applicable to their needs. We need to remember that there is significant diversity amongst people with disabilities as there is with any group: the needs of a woman living with physical disabilities with her family in a rural or remote area will naturally be different from the needs of a man with a cognitive impairment living alone in an urban area.

Lastly, when considering the most effective approaches to building the capacities of humanitarians to be more disability inclusive, in partnership with people with disabilities, it's important to look for methods beyond only training or awareness-raising sessions. This case study shows us a variety of other methods, including: workshops to develop disability inclusive tools and action plans, coaching humanitarian organisations (with persons with disabilities acting as coaches), peer-to-peer support sessions within coordination working groups, observation (where people with disabilities are observing and analysing responses), and piloting new tools in the field.



#### Changing attitudes requires local leadership

Long-held attitudes and the barriers for people with disabilities that come from these beliefs and behaviours are difficult to change. But the HI team in NES have learned that changing beliefs in communities is far more possible when communities can communicate directly with members of their own community living with disabilities. Listening to the lived experiences of people with disabilities and having an opportunity to engage in meaningful discussion on not only the barriers they face, but also their ideas to remove these barriers has helped communities recognise their fellow community members have many abilities and rights, as well as needs. That they are all part of the solutions to

make their communities more disability inclusive. It's important for us, as humanitarian practitioners, to recognise that some of these beliefs are shared within the humanitarian sector as well. We must acknowledge and be attentive to our own biases (and those of our colleagues), and work to mitigate these.

Discriminatory beliefs, attitudes, and stereotypes can take many years to shift and gradually transform. This means community outreach efforts need to be ongoing and evolving – this requires sustainable and reliable funding for goals to be achieved, discussed more below.



#### **Empowerment requires freedom to lead**

At the heart of it, HI's approach has been to support Inclusion Ambassadors to build their own skills and knowledge, which enables them to determine what action they wish to take (individually and collectively) within their communities to address barriers to disability

inclusion. After this, HI's role is to provide continued support, whether through skills-building, developing materials, providing resources and spaces for activities, or helping with planning. But it's the Ambassadors who take the lead and ask for what they need.

This independence, alongside the experiences Ambassadors continue to accrue, has only further empowered and enhanced their confidence in their capabilities and their valuable contributions and impacts within their communities. Some have also noticed significant changes within their families – as their confidence grows, and they communicate more, so has their family's understanding and respect for their opinions, needs, and contributions.

For many, a seed of empowerment came from learning, some for the first time, that they have rights they are entitled to – rights to dignity and equitable, meaningful participation in their communities, rights to have and pursue their own dreams. This growing knowledge and the realisations it has brought with it, has helped to feed their growing self-confidence in their right (and ability) to communicate and be listened to by their families, their neighbours, decision-makers, and even the wider public through media events.

It's not only individual empowerment that the Inclusion Ambassadors project has encouraged, but also collective empowerment. Over the time spent together, the Ambassadors have become a family, supporting each other, encouraging each other, even grieving together when they lost one of their own. The diversity within the overall group has not been without its challenges, reflecting the diversity with NES and the perspectives this diversity brings. But working through these challenges has been the ultimate strength of this group. Through this process they have learned from each other's experiences, their suffering and strength, and this has taught them things about themselves. They draw strength from one another. Approaching this project from a starting point of supporting people with disabilities to feel empowered, in control, and able to achieve their own goals was essential for the transformational journey the Ambassadors then bravely embarked upon.

#### Localisation and its challenges for people with disabilities

By its very nature, adopting a localised approach to disability inclusion means approaching the beginning a project with an open mind as to where it's headed – the point is to empower people with disabilities to determine for themselves what their priorities are, what actions they believe are will improve disability inclusion, and where they want to take things to achieve their objectives. To achieve these goals, capacity building is typically required. Localisation in this case is a process, not merely a destination, that can begin at the start of any project or programme. This case study highlights some of the challenges, as well as opportunities, this approach can present in humanitarian action.

"With love, a person carries on, and with love we overcome difficulties. After I met Hana, I knew this kind of love."

• • •

"I am no longer ashamed of my condition, because it is not a condition to be ashamed of. I did not choose it, and any human being could face it."

Disability inclusion efforts are usually best supported and encouraged by having specific focal points within organisations to ensure the specific needs of people with disabilities aren't subsumed within a wider group. These efforts are also assisted by hiring persons with disabilities as organisational staff, as we've learned in this case study. And where we ask people with disabilities to support our efforts to encourage disability inclusion in humanitarian action, we must have the resources to compensate them for their time and expertise.

In contexts where there are multiple physical barriers and accessibility issues (e.g., due to conflict and safety concerns with movement, large distances to travel and lack of suitable transportation, physical infrastructure barriers), organisations will need

to think and plan strategically to ensure these don't create obstacles to the goals of the project. This may, for example, require investment in creating physical infrastructure changes to venues for persons with disabilities to use.

As humanitarians, a localised approach to disability inclusion requires us letting control and power go and providing people with disabilities the freedom to lead in the directions they prioritise. This means not constraining any potential outcomes because they don't fall within our own programmatic parameters. In this story, some Inclusion Ambassadors wanted to engage in advocacy, some wanted to start their own businesses or gain employment, others wanted to return to their studies, many had multiple goals.

We can't anticipate where people with disabilities will take the skills and knowledge they have built and where they will seek to apply these skills at the very beginning of a project. Nor should we. To do so takes the power of decision-making away from the very people we are supporting to become more empowered to make those decisions themselves.

This requires us to provide sufficient latitude to allow these kinds of programs to grow incrementally, based on the emerging needs and wishes of people with disabilities as

they strengthen their capacity and derive strength, inspiration, and knowledge from each other. As humanitarian actors, we can advocate for funding approaches that provide flexibility, particularly in the early days, around those project goals and objectives.

It also requires a recognition that localisation in contexts where civil society has been torn apart through over a decade of conflict, violence, and widespread displacement, takes a very long time. There must be a degree of long-term funding to provide the safety and reliability of resources – to be able to trust that the actions taken can be sustained and built upon.

In NES, the only formal OPD is the Ambassador's Association. Today it operates in sixmonth increments; the rent for their office space is paid by each member. All of the work is voluntary. Many of its members are unemployed. Its existence hangs together through the sheer grit and determination of the people who brought it into existence.

This case study challenges us to ask the question – if we are committed to localisation, how can we do more for fledgling organisations like this and the many others like them throughout the world?



## Questions for you to reflect upon in your own disability-inclusion activities:

- How well do you understand the **specific barriers** people with disabilities face in your context? Have you conducted analysis using indicators and methods tailored to persons with disabilities?
- What **levels of engagement** do humanitarian organisations have with people with disabilities?
- How are persons with disabilities **organised** in your context? Are there **OPDs or informal networks** where they work together?
  - What is necessary for persons with disabilities to **meaningfully participate in humanitarian action**? What knowledge and skills do they need? What other support do they need?

5

How much **freedom do persons with disabilities have** to conduct their own analysis, planning and decision-making on activities to encourage disability inclusion?

6

Are you **co-designing activities** with people with disabilities or merely consulting?

7

Do you have the resources to **compensate people with disabilities** for their time and expertise?

8

How **sustainable** is your approach? Do people with disabilities have the knowledge and skills to pursue additional **funding opportunities**?



To find out more about this practice:

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#### **Annex: RAAL Labs**

## Review, Adapt and Action Learning Laboratories: RAAL Labs - A practical guide (See here)

This practical guide provides information on how to complement and combine training sessions on disability-inclusive programming with interactive laboratory style learning sessions, the Review, Adapt, and Action Learning Laboratories (RAAL Labs). RAAL Labs have proven to further boost humanitarian actors' confidence and skills to adapt their own programming tools and processes, aligning them with the IASC Guidelines.

This guidance was developed by people with experience facilitating training sessions and the RAAL Labs. The intended target group are technical and/or program staff who facilitate engaging learning opportunities for and with their teams with the objective to enhance skills, understanding and confidence around disability-inclusion in their humanitarian programming.

Examples of tried and tested methods can be found throughout the guide coupled with essential information that is required to plan and implement a RAAL Lab. In the annexes, you will find links and further practical resources, such as more in-depth details on topics covered and templates that can be used and adapted according to your needs and context.

Please contact inclusion@hi.org for any questions.

#### **Further resources**

**CBM Global**, *CBM Global*'s *Power Shift Journey: Working with a Localisation Steering Group*, February 15, 2023, https://cbm-global.org/blog/cbm-globals-power-shift-journey-working-with-a-localisation-steering-group

Humanitarian Needs Assessment Programme (HNAP) Syria, Disability in Syria: Investigation on the intersectional impacts of gender, age and a decade of conflict on persons with disabilities, 2021, https://www.hi-deutschland-projekte.de/lnob/wp-content/uploads/sites/2/2021/09/hnap-disability-in-syria-investigation-on-intersectional-impacts-2021.pdf

**Humanity & Inclusion,** *Syria Country Program*, https://www.hi.org/en/country/syria

**Inter-Agency Standing Committee**, *IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action*, 2019, https://interagencystandingcommittee. org/iasc-guidelines-on-inclusion-of-persons-with-disabilities-in-humanitarian-action-2019, specifically:

Chapter 3: What to do – Key Approaches to Programming ('Must-Do Actions')

**Chapter 6**: Cross-cutting considerations

Chapter 11: Camp coordination and camp management

Chapter 14: Livelihoods

Chapter 16: Protection

**Chapter 17**: Shelter and settlements

Chapter 18: Water, Sanitation, and Hygiene

**StephenPerry,** UKDepartmentforInternationalDevelopment(DFID),IOM,OCHA,UNHCR, UNICEF, WFP, WHO, *Guidance on strengthening disability inclusion in Humanitarian Response Plans*, 2020, https://www.globalprotectioncluster.org/publications/832/policyand-guidance/guidelines/guidance-strengthening-disability-inclusion

**UN General Assembly,** Convention on the Rights of Persons with Disabilities, A/RES/61/106, 24 January 2007, https://www.refworld.org/legal/resolution/unga/2007/en/49751

**Washington Group on Disability Statistics,** *Question* Sets, https://www.washingtongroup-disability.com/question-sets/