Self-reported barriers to activities of daily living of persons with disabilities living in IDP sites in northwest Syria

Lived experiences of persons with sensory, physical, and cognitive difficulties residing in unfinished buildings, collective centres, makeshift tents and formal camps

Brief report and recommendations

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Protection Cluster Syria (Turkey hub)
November 2020

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Executive summary

> ***'I don't demand my rights and don't interact with organizations, because only the strong get their rights. I am neglected, vulnerable and ignored'***

37 year-old male with mobility and/or self-care difficulties residing in an unfinished building

The impact of physical, attitudinal, and institutional barriers on access to essential services and participation in essential activities for persons with disabilities residing in IDP sites are often extreme in northwest Syria.

Barriers for persons with disabilities negatively impact mental and physical health and wellbeing, attainment of rights on an equal basis with others, access to services, and individual and household income sufficiency. For children, barriers significantly limit their ability to learn and develop along with their peers, with lifelong implications, rarely reversible. These barriers to accessing services and participation increase risks of adoption of negative and harmful coping strategies, elevate risks of exploitation and abuse, and increase poverty. Common compounding factors to existing barriers include income insufficiency, the impacts of displacement on access to assistive devices, and a general environmental incompatibility with needs of persons with disabilities.

Barriers and their consequences for individuals due to difficulties in functioning are often misunderstood. This report aims to describe lived experiences of persons with disabilities in northwest Syria, supporting understanding. It also highlights needs and key barriers to engagement in personal, domestic and community-based activities of daily living, which includes access to and engagement with humanitarian organisations. The analysis of these difficulties forms the basis of key pragmatic recommendations for humanitarian actors.

Findings demonstrate that persons with disabilities experience reduced independence in their daily activities due to:

- physical barriers such as - for example - inaccessible WASH facilities,
- attitudinal barriers, such as bullying and threats of abuse and exploitation in their local communities as well as discrimination from humanitarian staff, and
- institutional barriers, such as the lack of inclusion mechanisms in humanitarian programming which would enable persons with disabilities to participate on an equal basis with others, such as provision of reasonable accommodation (individualised supports).

Themes extracted from the data demonstrate that this group of respondents felt disempowered, made to feel lesser than others and therefore somewhat invisible in their communities. Findings also suggest that 'disempowered' and 'lesser than others' is, for the most part, also how community members perceive persons with disabilities. The power and impact of attitudes in the community, which includes those of humanitarian staff, cannot be overlooked, as almost all barriers are to a degree a result of intentional or unintentional discrimination.

The methodology to collect information in this study was qualitative and therefore, the results are not representative of the wider population with disabilities. However, key themes were prominent in the data and therefore quantified, only for the ease of the reader. Key findings are as below:

- 56 percent of respondents reported that due to the lack of available 'European style' toilets, they could not use toileting facilities at all
- 53 percent of respondents reported needing additional hygiene supplies

- 70 percent of respondents reported the need for an assistive device to improve their functioning in at least one of their daily activities
- 34 percent of respondents reported that they required personal assistance to mitigate barriers and access their local environment, while in the in the absence of another person to assist them they are commonly unable to leave their residence at all
- 41 percent of respondents reported incidents where they had experienced intentional or unintentional exploitation (usually due to a lack of consent procedures to film or to be photographed) and/or discrimination due to their disability when engaged with humanitarian organisations
- 45 percent of respondents reported that they were unaware of any complaints and feedback mechanisms available to humanitarian service users.

As a result of these findings and based on the most urgent needs reported by respondents of the study, the Inclusion Technical Working Group of the Syria Protection Cluster (Turkey hub), in line with the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action 2019, has developed key recommendations and actions in the form of a practical checklist which all humanitarian partners, including donors, should consider immediately. Additional checklists, specific to the sectors of Protection, WASH, S/NFI, CCCM (including site planning), Health, Food Security and Nutrition are also included.

These checklists build on, contextualize and operationalize the four 'must do actions' detailed in the IASC guidelines[1]:

Promote

1. *Promote meaningful participation* - engage persons with disabilities in all phases of the project cycle in a meaningful way, ensuring that input and feedback from persons with disabilities is acted upon.

Remove

2. *Remove barriers* - identify attitudinal, physical and institutional barriers to accessing assistance and services which exist in the community, the general context, and within your organisation and take measurable actions to remove these.

Empower

3. *Empower persons with disabilities* - provide persons with disabilities the opportunity to engage in the project in various capacities e.g. monitoring committees, as staff, local liaisons etc; and enable them an opportunity to develop their skills.

Disaggregate

4. *Disaggregate data for monitoring inclusion* - ensure that all data collected in assessments and implementation monitoring is disaggregated at a minimum by gender, age, and disability to better understand the extent to which persons with disabilities are reached and engaged in projects, and to provide information on gaps and needs to facilitate project adjustment.

Survey methodology and sample

Qualitative evidence regarding the lived experience for 71 internally displaced persons with disabilities and their care givers was collected through semi-structured interviews in 11 sub districts during June 2020. The sample includes 37 females (2 years old to 79 years old; mean age of 39.5 years) and 34 males (10 years old to 83 years old; mean age of 35 years). Of the total sample, 89 percent of respondents reported mobility and/or self-care difficulties, 17 percent intellectual and/or cognitive, 11 percent reported difficulties with vision, 10 percent hearing difficulties and 9 percent reported difficulties with communication.

[1] IASC (2019). Inclusion of Persons with Disabilities in Humanitarian Action

1. Contextual background

After nine years of conflict, the Syrian humanitarian crisis is one of the most significant crises of our time. Continued hostilities, new and protracted displacement, increased returns to Syria and the sustained destruction of communities has impacted the lives of Syrian's and their futures in a devasting way. The 2019 Humanitarian Needs Overview (HNO) identified that 11.06 million people were in need of some form of humanitarian assistance[2]. In October 2020, priority needs of internally displaced Syrian's residing in the northwest pertained to livelihoods, basic services and food. Half of the displaced population is reported to live in inadequate housing situations. These include substandard shelters such as unfinished buildings and emergency shelters provided by humanitarian partners such as tents. According to the CCCM Cluster, as of October 2020, 1.4 million internally displaced persons live in planned and informal self-settled sites.[3] For households which include persons with disabilities, priority needs include more specifically, electricity, health services and transport.[4] Further, in the context of the rapid deterioration of the Syrian Pound and the global pandemic, COVID-19, these needs are anticipated to increase even more so and hence the urgency to respond in a specific and relevant way is of the utmost importance.

Recent evidence suggests that the individual prevalence rate of persons with disabilities living in Syria, aged 12 years and above is 25% which is almost twice that of the global average.[5] In Aleppo and Idleb governorates, the individual IDP prevalence demonstrates that females are more likely to experience disability than males. That is, 59% of females and 27% of males (Aleppo) and 42% of females and 30% of males (Idleb) have disabilities.[6] With regards to age, across Syria, 74% of the population above the age of 54 years old has a disability.[7]

In light of these statistics and given barriers that persons with disabilities frequently face, ensuring that the humanitarian response is inclusive of all should be considered as an urgent priority for all humanitarian partners operating in northwest Syria. Specific situations of persons with disabilities and related humanitarian needs are often invisible, unidentified, and/or misunderstood.

Therefore, the following brief aims to describe the lived experience of persons with disabilities in northwest Syria and highlight needs and key barriers to engagement in personal, domestic and community-based activities of daily living, which includes access to and engagement with humanitarian organisations. The analysis of these difficulties forms the basis of key pragmatic recommendations for humanitarian actors.

2. Brief methodology

Key informant interviews (KIIs) were conducted with internally displaced persons with disabilities residing in 11 sub districts in inadequate living situations throughout northwest Syria over the phone by humanitarian staff who have a background in disability and inclusion. For those key informants who have hearing and communication difficulties, a support person was present to aid the interaction over the phone and often video call was used.

The KII's were conducted during the time of severe restrictions on movements to staff and beneficiaries due to COVID-19 related safety measures. Inclusion criterion for participants was defined as having significant functional difficulty with one or more areas of daily functioning congruent with the Washington Group short set domains of functioning which are: communication, hearing, cognition, self-care, mobility and vision.[8]

For further details related to the methodology, including consent procedures and study limitations, please refer to Annex A.

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[2] HNO (2019) Syrian Arab Republic
[3] CCCM Cluster, ISIMM data (September 2020); see also HNAP, October 2020 Mobility and Needs Monitoring NSAG & TBAF controlled areas (November 2020).
[4] HNAP (2020) Summer Report Series – Disability Overview
[5] Ibid
[6] HNAP (2019) IDP insight: Disability
[7] Ibid
[8] Washington Group on Disability Statistics (2001). Washington Group Short Set of questions. Retrieved from: https://www.washingtongroup-disability.com/question-sets/wg-short-set-on-functioning-wg-ss/

Analytical framework

The Canadian Model of Occupational Performance and Engagement (CMOP-E) was used as an analytical framework to conduct a thematic analysis of the translated KII scripts. The CMOP-E is an occupational performance framework designed to understand the contributing factors which influence how an individual performs daily activities.[9] This framework enabled researchers to understand the barriers persons with disabilities experience when engaging in Activities of Daily Living (ADLs). These barriers (physical, attitudinal and institutional)[i] are recognised within the human rights model of disability and consequently depict where the interaction between impairment and environment creates exclusion and ultimately denial of rights.[10]

Characteristics of the sample

71 persons with disabilities and/or their primary caregiver were interviewed (dependent on age) and their results recorded. This includes 37 females, where their ages range from 2 years old to 79 years old, with the mean age being 39.5 years; and 34 males, where their ages range from 10 years old to 83 years old, with the mean age being 35 years.

Of the total sample, 89 percent of respondents reported mobility and/or self-care difficulty, 17 percent intellectual and/or cognitive difficulty, 11 percent reported difficulties with vision, 10 percent hearing difficulties and 9 percent reported difficulties with communication.

Of the total sample, 9 (13 %) people reside in makeshift accommodation, 16 (23%) in formal camp settings, 17 (23%) in collective centres and 29 (41%) in unfinished buildings.

3. Survey findings – lived experiences

The impact that barriers have on participation in both basic and complex activities of daily living for persons with disabilities can be extreme. Barriers impact mental and physical health, access to rights on an equal basis with others, individual and household income sufficiency and for children, barriers significantly limit their ability to learn and develop along with their peers, which has lifelong implications, rarely reversible. These barriers to participation increase risks of negative coping strategies, poverty and exploitation and abuse.

The major barriers to engagement in ADLs, including engagement with humanitarian organisations, which emerged from the data, relate to attitudinal, physical and institutional barriers experienced by individuals in their residences and their local communities. Common compounding factors to barriers include income insufficiency, the impacts of displacement on assistive device availability and general environmental incompatibility with needs. In combination with the aforementioned barriers, this interplay has resulted in dire health consequences in some circumstances where reduced access due to the humanitarian situation has meant worsening of previously managed health conditions.

3.1 Personal activities of daily living

3.1.1 Physical barriers to personal activities of daily living: toileting, bathing, sleeping, eating and meal preparation

Toileting, diaper use, and bathing

The most significant barriers to using toileting and bathing facilities are reported to be both the distance between accommodation and latrines and inaccessible design of facilities.

56 percent of respondents report that due to the lack of available 'European style' toilets, they could not use toileting facilities at all. The primary reason for this was described as the inability to physically squat down to toilet which commonly resulted in using diapers instead of toileting safely. These difficulties have consequences for the health of the individual and these consequences impact the whole familial unit.

'[My] difficulties are due to the lack of appropriate facilities such as a toilet seat and a suitable bathroom'

15 year-old male with mobility and/or self-care difficulties residing in a formal camp

[9] Townsend, E., & Polatajko, H. (2007). Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation. Ottawa: CAOT Publishers

[10] United Nations Convention on the Rights of Persons with Disabilities (2006)

Important to note is that diaper use is associated with increased risk of extreme discomfort, feelings of loss of dignity, urinary tract infection and skin irritation which can lead to skin breakdown and in many cases, particularly where the individual is not regularly mobile, skin ulceration and serious infection.[11] Once ulceration and skin infection occur, medical treatment is necessary and if left untreated, ulcers can lead to the need for urgent surgical intervention and, in some cases, death.[12]

Particularly in the absence of accessible bathing facilities (as regular bathing reduces the risk of infection), those using diapers frequently are at an increased and unnecessary risk of secondary health conditions.13 Further, the availability of diapers is often scarce in some areas and when available, the cost impacts the entire familial unit and represents an additional financial burden in already largely income insufficient households. Some respondents have reported using old cloth and other recycled materials instead, however, this only further increases health risks for the individual.

In regard to bathing facilities, due to the reported small spaces and general inaccessible design, often respondents could not access bathing facilities. Very often respondents reported that they needed the assistance of another person to safely bathe and dress and given the small spaces available this was not possible.

Need for compensatory supplies related to toileting and bathing

In order to maintain hygiene in the context of the current barriers, 53 percent of persons with disabilities reported needing additional hygiene supplies. These include skin moisturiser to maintain skin integrity, adult diapers, additional women's hygiene products, additional clothes to remain clean and dry and additional cleaning products for the living space.

Sleeping

In many cases, sleeping on the ground (on a sleeping mat) is aggravating toileting difficulties overnight, due to the difficulty to get in and out of bed independently and, reach an accessible toilet. Overnight toileting difficulties and incontinence can cause serious health conditions, but also impacts both the individual and the family negatively, given families are sharing small spaces together.

Other common difficulties with regards to sleep were related to the type of mattress available. Persons who have specific health conditions and older persons, are often at risk of pressure sores (bed sores) whilst in the lying position for long periods of time. There are mattresses which help relieve pressure when the individual is not able to naturally do so themselves. In the absence of this, individuals are at risk of pressure ulcers and other conditions which require medical attention.[14]

'Instead of diapers, the family uses pieces of cloth and clothes that cause major infections…'

17 year-old male with intellectual and/or cognitive, hearing and mobility and/or self-care difficulties residing in a formal camp

'I have a difficulty completing all these [self-care] activities without a lot of help, I cannot use the toilet, so I wear diapers. but I cannot afford to buy them'

20 year-old-female with visual and mobility and/or self-care difficulties residing in a formal camp

'I struggle in terms of distance to the latrines, especially at night, and the fact that the toilets are shared. I have difficulties in terms of needing to be carried to the toilet and need a European style toilet'

52 year-old male with mobility and/or self-care difficulties residing in a formal camp

'I can't toilet, shower, or do anything on my own……I also use urinary catheters and diapers, and I suffer from severe ulcers'

30 year-old male with visual and mobility and/or self-care difficulties, resident of an unfinished building

'I sleep on the floor, and I find it difficult getting up and sitting up. Being diabetic and taking a diuretic medicine, I need to get up often to go to the toilet'

60 year-old female with mobility and/or self-care difficulties residing in an unfinished building

'I sleep on the floor with my family in the same tent. Before displacement, I used to have a bed and special mattress for bed sores, which I urgently need today'.

18 year-old male with physical, visual, hearing, communication and intellectual and/or cognitive difficulties residing in a makeshift tent

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[11] National Health Service (2020). Overview: Pressure ulcers (pressure sores). Retrieved from: https://www.nhs.uk/conditions/pressure-sores/

[12] Kirman, N. (2020) What is the mortality rate for pressure injuries (pressure ulcers)? Retrieved from: https://www.medscape.com/answers/190115-82434/what-is-the-mortality-rate-for-pressure-injuries-pressure-ulcers#:~:text=Each%20year%2C%20approximately%2060%2C000%20people,risk%20of%20mortality%20to%2055%25

[13] The Urology Group (2012). UTI Increases with age. Retrieved from: https://www.urologygroup.com/uti-risk-increases-with-age/

[14] Ibid

Eating and meal preparation

The final self-care activity discussed in the KII's was in relation to eating and meal preparation. The most significant challenges reported relate to difficulty swallowing ready meals and other types of food due to incompatible food textures, difficulty using hands to eat independently / to feed oneself, and dependency in meal preparation.

Swallowing

Often for people with difficulties such as dysphagia (which is a clinical condition describing a difficulty swallowing food and drink), the texture of food can represent a serious health and safety risk.[15] For example, tough textured food such as meats and Arab bread can make it very difficult to swallow and can result in choking and/or aspiration (where the food enters the lungs instead of the stomach). Aspiration of food, if untreated, commonly results in chest infection and ultimately pneumonia, among other life-threatening conditions, which require medical attention.[16] Further, many respondents reported that due to an injury, that they also needed smooth textured food, but this was not often available or affordable.

Feeding oneself

Lack of independence when feeding oneself is a serious daily challenge for individuals with a broad ranging number of functional difficulties. Often people with hand and/or arm weakness, reduced arm/hand coordination, reduced sensation and/or reduced activity tolerance can experience great difficulties with feeding themselves and this can result in feelings of loss of dignity, self-esteem and autonomy. As being assisted with feeding is often associated with children, this can be devastating for an adult and impact their self-perception and ultimately their mental health, but also, on a more practical note, this impedes their daily independence resulting in a need to be assisted by another person. For children with difficulty feeding, the missed opportunity to learn how to feed oneself in an adapted way, can mean that the child does not learn this skill at all, which can result in continued dependence on another person into adult life.

Meal preparation

The majority of respondents reported that due to small and shared spaces and the physical inaccessibility of meal preparation areas, a family member was responsible for preparation of meals. This impacts the independence of persons with disabilities significantly and again highlights the reliance they must often have on another person for essential activities of daily living.

'I have difficulty related to food and eating because it is shared with other families and the food served is ready meals, so the type of food available is sometimes difficult to swallow'

50 year-old male with physical, intellectual and/or cognitive and communication difficulties residing in a collective centre

'I have difficulty eating on my own and also need a specific type of food, like bananas, which I can't afford with no breadwinner in the family'

45 year-old female with physical and intellectual and/or cognitive difficulties, residing in a formal camp

'I cannot prepare food, and I can only eat pureed food that is easy to chew and swallow; financial restrictions prevent my family from buying the food that is suitable for me'

79 year-old male with physical and intellectual and/or cognitive difficulties, residing in an unfinished building

'He has great difficulty in accessing food, eating and moving, as he requires permanent help; he cannot hold the spoon in his hand'.

Primary care giver on behalf of 16 year-old male with intellectual and/or cognitive difficulties residing in a makeshift tent

'There is a great difficulty when it comes to eating …. I can't use my hands so well'

14 year-old male with physical and communication difficulties residing in a collective centre

[15] Dysphagia: Overview. Retrieved from: https://www.mayoclinic.org/diseases-conditions/dysphagia/symptoms-causes/syc-20372028
[16] Ibid

3.1.2 Attitudinal barriers to personal activities of daily living

Community perception and behaviour

Both male and female key informants reported experiencing attitudinal barriers to accessing facilities outside of their dwelling, including toileting and bathing facilities. There are frequent complaints of fears of bullying and abuse from others in the community when attempting to access facilities, which is a significant deterrent.

Further, feelings of shame and fear of being pitied by others when using assistive devices to access facilities in the community were also commonly expressed – this also prevents people from using communal facilities.

It is important to note that attitudinal barriers significantly contribute to the existence of physical barriers described above while also posing a major obstacle to inclusion and participation. Attitudinal barriers stem from behaviours in the community and are often based on assumptions due to lack of knowledge, ignorance, stereotyping, prejudice, and even discrimination – persons with disabilities frequently are only seen in terms of his/her disability.

Fears of sexual abuse and exploitation

Many female key informants also reported fear of sexual abuse and exploitation when using toileting and bathing facilities and again reported the need for a companion. Commonly these fears were linked to the fact that facilities were shared between men and women which, in their opinion, increased the threat of violations and harassment.

(see for further details sections below)

'I do not have any difficulties within the house, as I am used to the place and know the details of the house. As for outside, I cannot go out without an escort and do not use an assistive device for fear of verbal abuse by people around me'.

29 year-old female with visual difficulties, residing in an unfinished building

'I have toileting and bathing difficulties, but dressing is manageable. There is physical difficulty and I notice the pitying looks of others'

37 year-old male with mobility and/or self-care difficulties, resident of a makeshift tent

'[It's difficult because of] issues related to culture and community perception'.

35 year- old male with physical, intellectual and/or cognitive difficulties, residing in a collective centre

'I have some concerns regarding sexual exploitation and abuse because the toilets are shared'

18 year-old female, with hearing difficulties residing in a collective centre

'Due to the nature of the place and the large number of families sharing a bathroom and a toilet, [I have] fears that [my daughter] will be sexually abused or exploited, therefore, she cannot go alone'

Caregiver of 12 year-old female with hearing and communication difficulties, residing in a collective centre

'I can perform all of the above without help, but I do have some concerns regarding sexual exploitation and abuse when using the shared toilets/restrooms'

16 year-old female with mobility and/or self-care difficulties, residing in a collective centre

3.2 Community activities of daily living

3.2.1 Physical, attitudinal and institutional barriers to community activities of daily living: securing food, and accessing transport

Securing food

The most significant difficulties reported in relation to securing food were around the long distances to food sources, physically carrying items and fear of abuse and exploitation in the local community when seeking food.

For many persons with disabilities, physically carrying food parcels (assistance or purchases) is difficult or impossible due to reduced mobility and the associated risks of harm, such as falls and injury. For persons with visual and/or intellectual or cognitive impairment, navigating their way to and from (as well as around) a shop and especially food distribution site is often extremely challenging, particularly for those who are newly displaced and therefore unfamiliar with their environment.

The added perceived threat of abuse and exploitation by community members means that the majority of people with disabilities hesitate or do not access food sources independently.

Service access

The physical terrain in many areas of northwest Syria is often inaccessible for persons with disabilities. This is due to uneven ground surfaces and rocky terrain in some parts, wet and muddy walkways in winter, uneven roads and lack of clear visual cues to assist persons with visual difficulties. For those who experience functional difficulties in these environments, this often results in avoidance of leaving the home at all, unless another person can provide significant physical support, for example by carrying the individual.

Further to this, universal design[ii] of service facilities is lacking, creating a significant barrier to service access. Many respondents report that they cannot access services because they are unable to access the physical facilities where those services are provided. Examples of required adaptations include, ramp access, wide doorways, accessible toileting facilities and communication and visual cues.

'I have difficulty in accessing food due to the distance of the place'

30 year-old male with mobility and/or self-care difficulties residing in a makeshift tent

'I have no access to food; I ask my children to get what I need and I do not move unless absolutely necessary'

38 year-old male with mobility and/or self-care difficulties residing in a formal camp

'I do not leave the house unless absolutely necessary and need help securing food since I have mobility and financial difficulties; neighbours help me with food and rainwater… I get awkward looks from people when I'm outside'

24 year-old male with mobility and/or self-care difficulties residing in an unfinished building

'I move around the house using my hands since I have paraplegia. As for the outside, I do not go out unless absolutely necessary… It is difficult to walk around the area so they carry me to/ from the car to/from the door of the house'

40 year-old female with mobility and/or self-care difficulties residing in an unfinished building

'I have daily mobility difficulties that are especially related to the area I live in, which is rugged, and therefore, I move with difficulty within that area'

15 year-old male with mobility and/or self-care difficulties in a formal camp

'Difficulty in securing supplies and taking her to a treatment centre because of the distance of the centre'

Care giver of two year-old female with mobility and/or self-care difficulties in a formal camp

Communication

Communication with staff remains a key challenge to engagement. As persons with disabilities may rely on non-verbal communication, staff are often not able to accommodate these needs. This represents concerns regarding equal access to services, but also denial of the right to consent to service engagement and having their specific needs met. Important to note, is that the lack of understanding of various conditions and how these may appear to staff outwardly can impact the staff/service user interaction significantly. For example, for a person with speech difficulties, staff may assume this person may also have significant cognitive impairment affecting interactions. This misconception may lead to significant impediments on basic rights such as the inadvertent denial of an opportunity to provide informed consent (people with cognitive impairment should still be enabled to provide informed consent). Similarly, a person with a mental health condition or an intellectual disability may be perceived as a threat to staff due to misconceptions and stigma, and therefore, their right to service access or informed consent may also be denied.

Transport

Respondents most reported that lack of access to transport is due to its high cost. Other barriers are related to availability and physical accessibility of transport options. Available transport was more commonly reported inside camps, however the physical accessibility of all forms of transport is a key challenge for many.

Personal (caregiver) support

34 percent of respondents reported that they required assistance to mitigate barriers and access their local environment. In the absence of another person to assist them, persons with disabilities are commonly unable to leave their residence. The need for personal support on transport also raises the issues of increased cost to travel, which is required for two people instead of one. Where there is no support person available, persons with disabilities can experience compounded isolation from their community, including reduced access to essential services.

Access to assistive devices

70 percent of persons interviewed reported the need for an assistive device to improve their functioning in at least one of their daily activities. Assistive devices and technologies have the primary purpose of maintaining or improving an individual's functioning and independence to facilitate participation and to enhance overall well-being.[17] They can also help prevent impairments and secondary health conditions. These include mobility and self-care devices in addition to adapted devices such as adapted cutlery or technologies to improve sleeping. For many persons with disabilities, in the absence of a device, they are unable to function independently or at all. This reduced function poses a significant risk of loss of independence and the onset of secondary health conditions, including mental health conditions.

'I cannot access services due to the nature of my mental condition, and the communication difficulties due to my speech and hearing impairments'

18 year-old male with hearing, communication, intellectual and/or cognitive and visual difficulties residing in a makeshift tent

'I have difficulty accessing services due to my poor communication abilities'

50 year-old male with physical, intellectual and/or cognitive and communication difficulties, residing in a collective centre

'I suffer great difficulty and pain when using transportation or accessing to services. I also face challenges in using transportation because of the high cost'

35 year-old male with mobility and/or self-care difficulties residing in an unfinished building

'I can't access service centres due to the high transportation costs'

16 year-old female with mobility and/or self-care difficulties residing in a collective centre

'It is difficult to walk around the camp…and I also can't use transport, it costs a lot'

45 year-old female with mobility and/or self-care difficulties residing in a formal camp

'I cannot access services or use transport without the help of a companion'

83 year-old male with physical, visual, and hearing difficulties residing in a makeshift tent

'I face great difficulties in this regard because I cannot access services or use transportation on my own, as I can suddenly lose memory and get disoriented and won't know how to return to the camp'.

50 year-old male with physical and intellectual and/or cognitive difficulties residing in a formal camp

'I cannot use transport or access services except with the help of others. I suffer from not having a permanent caregiver because my wife is sick and sometimes cannot help'

66 year-old male with mobility and/or self-care difficulties residing in a formal camp

'I do not have any devices to help me move around and the facilities are far from the place where we live so I need to walk, for example, the toilet is so far'

62-year-old female with mobility and/or self-care difficulties, residing in a collective centre

[17] WHO (2020). Disability: Assistive Devices and Technologies

3.2.2 Barriers to accessing and engagement with humanitarian organisations

Staff engagement and complaints and feedback mechanisms

The KII questionnaire included questions designed to define the experience of difficulties when interacting with humanitarian staff and accessing and using complaints and feedback mechanisms. Results demonstrate that barriers relate to awareness of staff pertaining to the needs of persons with disabilities, instances of exploitation impacting confidence in the organisation and inaccessible complaints and feedback mechanisms, which was underpinned by feelings of futility about complaining or providing feedback at all.

Lack of awareness and discrimination

Many respondents reported that due to staff's general lack of awareness of persons with disabilities and their needs they often felt ignored and underserved due to their disability. Data indicates that respondents see the combination of low staff awareness related to persons with disabilities and related needs, as well as a lack of skills to communicate with persons with diverse communication needs, as reasons for persons with disabilities often being excluded from services. This combination of inadequate knowledge and skills may give rise to negative attitudes towards persons with disabilities and engender discrimination as confirmed by reported experiences of persons with disabilities.

Exploitation, discrimination, and negligence

41 percent of respondents reported incidences where they had experienced exploitation (usually due to a lack of consent procedures to film or to be photographed) and/or discrimination due to their disability. These experiences, in combination with other experienced barriers and challenges, left respondents feeling frustrated and exploited, resulting in a loss of confidence in humanitarian services.

Complaint and feedback mechanisms (CFMs)

45 percent of respondents reported that they were unaware of any CFMs available to humanitarian service users. Other difficulties include not being able to practically use the CFM mechanism due to physical inaccessibility and/or fear of complaining. For those who had provided feedback or complained, many respondents expressed feelings of futility regarding the CFMs' effectiveness.

'I don't demand my rights and don't interact with organizations, because only the strong get their rights. I am neglected, vulnerable and ignored'

37 year-old male with mobility and/or self-care difficulties residing in an unfinished building

'[I have] difficulty interacting [with humanitarian organisations] in addition to negligence. My wife communicates on my behalf. There are no fears, but there is discrimination; they do not register data for people with disabilities'

35 year-old male with physical, intellectual and/or cognitive difficulties residing in a collective centre

'I have difficulty interacting with humanitarian workers and organizations, as they often ignore me because they can't understand what I'm saying or understand my condition'

18 year-old male with hearing, visual, intellectual and/or cognitive and communication difficulties residing in a formal camp

'We suffer from the neglect of humanitarian workers. We need community inclusion activities in order to be included by the society and not excluded by our community'

29 year-old male with visual difficulties residing in an unfinished building

'I encountered several incidents with humanitarian organizations where I felt exploited when they came to film and take pictures, then they left and never came back'

Care giver of 10 year-old female with mobility and/or self-care difficulties residing in a collective centre

'I do not know the complaint mechanism, but I know that there is someone in charge of that. I don't think I am able to complain …I'm scared, I am afraid to file a complaint'

30 year-old male with physical and visual difficulties residing in an unfinished building

'I do not know how to file a complaint, nor do I have the ability to do so. The mechanisms are not available, and I do not know any of the staff. I am not comfortable to complain'

24 year-old male with mobility and/or self-care difficulties residing in an unfinished building

'I have a complaint, but I'd rather complain to God. I have no confidence in the complaint mechanism. I can file a complaint and have done so many times, but it was in vain'

38-year-old male with mobility and/or self-care difficulties residing in a formal camp).

3.2.3 Community based attitudinal barriers to community activities of daily living

Sexual exploitation, bullying and abuse

The intersectionality of gender, age and disability has a clear impact on feelings of vulnerability related to sexual exploitation and abuse. It is well understood that female gender often represents increased vulnerability to abuses of this kind, and with the compounding features of age and disability, individual vulnerability is exacerbated.[18] It is clear that the perceived threat of violations, impacts daily functioning and opportunities for engagement for persons with disabilities. Where reduced physical or cognitive function of people across all ages was commonly cited as a key reason as to why perceived vulnerability was increased. The impact of this threat is a key barrier to engaging in local environments, including external WASH facilities and accessing humanitarian services.

Stigma related to disability and the resulting discrimination faced by persons with disabilities, can occur both within the home and in communities.[19] Respondents commonly reported bullying and verbal abuse in their communities related to their functional difficulty specifically. Many respondents reported this to be a key reason for avoiding leaving their residence and engaging with their communities independently.

'She cannot be left alone due to fear of sexual exploitation or abuse, so her hair is shaved in order to make her look like a boy'

Care giver of 12-year-old female with intellectual difficulties, residing in an unfinished building

'As for outside, I cannot go out without an escort and do not use an assistive device for fear of verbal abuse by people around me… I do not use transportation on my own unless I am accompanied by someone, as I can't see where I'm going and I'm afraid of getting exploited or abused while using public transportation'

29-year-old female with visual difficulties residing in an unfinished building

'As for sexual assault, I have never been subjected to this, but if it happens, I will not be able to protect myself'

35-year-old male with mobility and/or self-care difficulties residing in an unfinished building

'I was abused once while in a car and I get dirty looks'

35-year-old female with mobility and/or self-care difficulties residing in an unfinished building

4. Conclusion

Internally displaced persons with disabilities residing in northwest Syria find themselves in situations of elevated vulnerability due to attitudinal, physical and institutional barriers. These barriers can in extreme cases lead to health-related risks, and most frequently result in exclusion and perceived threats from community members, often impacting on wellbeing and dignity. For children specifically, these barriers can have severe negative impacts on their ability to learn and develop along with their peers, with lifelong implications, rarely reversible. Persons with disabilities express feeling 'disempowered' and 'lesser than others' while this is, for the most part, also how community members are understood to approach persons with disabilities. The power of attitudes in the community, which includes those of humanitarian staff, should not be overlooked, as nearly all identified barriers are influenced by an element of intentional or unintentional discrimination.

Lived experiences of persons with disabilities vary significantly. Therefore, the intersectionality of gender, age and disability is crucial to consider when assessing and reducing barriers across the humanitarian response – humanitarian partners should recognise that people often simply labelled as 'persons with disabilities' are not a homogenous group and experience barriers differently across the course of their life, for example attitudinal barriers are commonly impacted by gender and age.

Due to the diverse and robust nature of the barriers to access and participation for persons with disabilities in northwest Syria, in the absence of both strengthened systematic inclusion mechanisms throughout the humanitarian response and implementation of individualised supports to equalise opportunities, persons with disabilities will remain isolated, suffering discrimination and denial of their rights in silence, often invisible to the wider community, including humanitarian actors.

[18] UN Department of Economic and Social Affairs (2020). Disability: Women and Girls with Disabilities. Retrieved from: https://www.un.org/development/desa/disabilities/issues/women-and-girls-with-disabilities.html

[19] American Psychological Association (2020). Abuse of Women with Disabilities. Retrieved from: https://www.apa.org/topics/violence/women-disabilities

Limitations in understanding the situation and specific needs of persons with disabilities in northwest Syria persist, and further investigation is required to deepen understanding and the identify resulting response measures. To contribute to this, protection monitoring, qualitative and quantitative data collection on prevalence of barriers, and monitoring of the status of persons with disabilities and their capacities for resilience are required. Moreover, to ensure identification and reduction of barriers at humanitarian programmatic level, as well as ensure effective inclusion of persons with disabilities of all ages and genders, humanitarian partners should at a bare minimum ensure sufficient and meaningful qualitative engagement with persons with disabilities, make efforts to develop staffing capacities, adhere to the IASC 'must do actions' and other recommendations (see below), and cultivate an organizational culture of inclusion in accordance with the basis of all humanitarian action: the protection of fundamental rights of all persons affected by a crisis.

5. Recommendations

In line with the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action (2019) organisations delivering humanitarian services in northwest Syria must consider the needs of persons with disabilities when designing and implementing humanitarian projects. To understand specific needs – which often relate to highly specific geographical and situational contexts – and respond accordingly, humanitarian organisations must make all efforts to identify barriers faced by persons with disabilities when accessing humanitarian assistance and services in northwest Syria and take proactive measures to mitigate these barriers with the ultimate goal of enabling equal access and participation of all individuals regardless of disability. Humanitarian organizations should capture access, participation, and actions taken in indicators to facilitate measurement, ensure accountability, and stimulate learning.

The IASC Guidelines set out four top line **'must do actions'** which should applies to all actors in every sector. These include:

Promote

Remove

Empower

Disaggregate

1. *Promote meaningful participation* - engage persons with disabilities in all phases of the project cycle in a meaningful way, ensuring that input and feedback from persons with disabilities is acted upon.
2. *Remove barriers* - identify attitudinal, physical and institutional barriers to accessing assistance and services which exist in the community, the general context, and within your organisation and take measurable actions to remove these.
3. *Empower persons with disabilities* - provide persons with disabilities the opportunity to engage in the project in various capacities e.g. monitoring committees, as staff, local liaisons etc; and enable them an opportunity to develop their skills.
4. *Disaggregate data for monitoring inclusion* - ensure that all data collected in assessments and implementation monitoring is disaggregated at a minimum by gender, age, and disability to better understand the extent to which persons with disabilities are reached and engaged in projects, and to provide information on gaps and needs to facilitate project adjustment.

In line with the IASC guidelines and building on the reported barriers specific to internally displaced persons with disabilities in northwest Syria, this report puts forward recommendations to the broader humanitarian community from the Protection Cluster Inclusion Technical Working Group. These recommendations are listed on the following pages and are put forward in three types of checklists:

- **a general cross-sectoral checklist for all humanitarian partners in northwest Syria, detailing practical minimum actions to ensure inclusion of persons with disabilities (in addition to the abovementioned 'must do actions'),**
- **sector specific checklists with practical recommendations based on findings of the report, and**
- **a checklist which puts forward recommendations to donors.**

Donors - key recommendations on inclusion

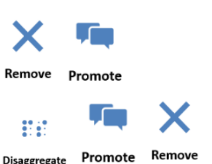
Relates to 'must do actions'

- ✓ Develop a holistic organisational **inclusion strategy**. Ensure the strategy addresses both the specific challenges and intersecting vulnerabilities experienced by persons with disabilities, with specific regard to gender and age, ensuring that barriers to participation are mitigated and the rights of persons with disabilities are upheld throughout all organisational actions. Ensure that implementing partner's address inclusion in their strategy and activities.

- ✓ **Promote the rights of persons with disabilities through all actions**, ensuring that partners adhere to clear standards, guidelines and indicators which ensure persons with disabilities are consulted, included and their participation is monitored throughout the project cycle. This includes encouraging partners to develop results monitoring and evaluation frameworks to measure the extent to which the rights of persons with disabilities are upheld and enable development of corrective actions.

- ✓ Allocate sustainable and adequate **funding for inclusion integration and mainstreaming** in the response to address the needs of persons with disabilities. Funding should support system reform to better align the response with the IASC Guidelines on Inclusion of Persons with Disabilities in Humanitarian Action. This includes integration of enabling actions to identify specific needs of individuals at the service level and provide individualised supports to mitigate barriers to participation such as assistive devices and transport allowances for the individual and their care giver.

- ✓ Ensure **specialised services** for all persons with disabilities, across all age ranges, such as functional rehabilitation, the provision of assistive devices and MHPSS services are made available and sustained.
- ✓ Ensure **children, youth and older persons with disabilities** are not overlooked and are able to access urgent services on an equal basis with others, through promoting an inclusive humanitarian response.



All sectors/actors - key recommendations on inclusion

Relates to IASC 'must do actions'

- ✓ Organisations and clusters should complete a **barriers and facilitators assessment** in the communities in which they operate. This assessment should inform specific actions taken, which are in line with the barriers and facilitators reported by persons with disabilities.

Remove Disaggregate

- ✓ **Develop a programme specific as well as organizational inclusion strategy** to overcome barriers and build on facilitators, *inter alia* those identified in the barriers and facilitators assessment.

Remove Promote Empower Disaggregate

- ✓ **Mitigate negative attitudes and misconceptions** amongst humanitarian staff by ensuring that staff are sensitized to the human rights approach to disability in humanitarian action, the rights of persons with disabilities and common barriers to participation in services, including the consequences of these, should they not be mitigated.

Remove

- ✓ Ensure staff have the **skills to include persons with disabilities**, by providing training on the identification of persons with disabilities, how to utilise diverse communication methods and how to meet their specific needs, including the ability to make referrals to other services where indicated.

Remove

- ✓ Assign an inclusion **focal point** within each project and/or office. This staff member would be responsible for ensuring accessibility and inclusion, engagement with- and empowerment of persons with disabilities, project monitoring and evaluation with an inclusion lens, etc.

Remove Promote Empower Disaggregate

- ✓ The use of sign language is uncommon among communities in northwest Syria and therefore, consult with communities to ensure contextually appropriate **diverse communication** alternatives are available. At a minimum, ensure augmentative and alternative communication devices (AACs)[iii] are available to support people who are non-verbal to enable basic interactions with staff, including the ability to provide informed consent.

Remove

- ✓ Ensure physical facilities are designed in line with the principles of **universal design** drawing on the International Organisation for Standardization (ISO) standards.[20] Where this is not possible from the outset, consult an experienced engineer in consultation with an inclusion professional, whom have strong experience in environmental adaptations for people with diverse abilities, to explore where temporary measures may be taken to promote physical access to facilities, such as portable ramps, grab rails, commodes[iv] and 'over the toilet frames'.[v] Provide safe lighting and accessible signage in all environments.

Remove

- ✓ Consider **accessible transport options** and, where applicable, the provision of transport allowances for the individual and their care giver, in cases where financial barriers limit access.

Remove

- ✓ Advocate to local authorities for the improvement of **public transport** availability and coordination, and for the improvement in **road and pathway quality** to enable safe access; use of the existing VIP lanes for persons with disabilities who require urgent access to services should be considered, ensuring protection mechanisms are put in place.

Remove

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[20] ISO (2020). Building Construction: Accessibility and useability of the built environment guidelines. Can be downloaded from: https://www.humanitarianresponse.info/en/operations/stima/inclusion-technical-working-group

- ✓ **Promote the rights of persons with disabilities in the communities** in which you work through awareness raising campaigns, engaging, prominent community figures and persons with disabilities themselves, to reduce the stigma and discrimination faced by persons with disabilities and promote equal participation.

Remove Promote Empower

- ✓ Ensure measures are in place to ensure that all staff collecting testimonials, pictures and videos are doing so without violating peoples' right to **informed consent**. Organisational policy and protocols for protection of this kind, should be aligned with relevant resources, such as UNICEF's guidelines for journalists reporting on children (and others).

Remove

- ✓ Ensure all **complaints and feedback mechanisms are known, understood and accessible for persons with disabilities** and that follow up and feedback to the individual/family is completed.

Remove Promote

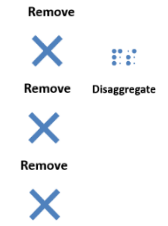
- ✓ Ensure **disaggregated monitoring and evaluation** of projects, specifically measuring access for persons with disabilities through both quantitative and qualitative monitoring and evaluation.

Remove Promote Empower Disaggregate

Protection - key recommendations on inclusion

Relates to 'must do actions'

- ✓ Protection programs should help to facilitate the meaningful participation of persons with disabilities in all process related to decisions which impact their lives while in displacement. Such meaningful engagement would contribute to understand better the needs and capacities and accordingly ensure evidence-based planning for interventions. Protection programs should also strive to empower persons with disabilities and their communities to identify community based sustainable solutions for deep rooted social issues.
- ✓ Develop outreach activities, including community-based outreach, to reach individuals who are isolated in their place of residence.
- ✓ Include case studies and discussions of disability in core trainings for protection staff, community outreach staff, protection focal points and protection committees.



- ✓ Monitor and report on violations of the rights of persons with disabilities. Include targeted violence, forced medical treatment, disability-related discrimination and barriers to accessing protection services.
- ✓ Integrate and mainstream content about persons with disabilities in core GBV training packages. Add case studies and discussions of disability to practitioner training and community awareness-raising materials.
- ✓ Women with disabilities may need access to flexible and diverse menstrual hygiene management materials. Adapt menstrual hygiene materials to meet their requirements. Consider supplying absorbent cotton pads, disposable or reusable sanitary pads, underwear, soap, a dedicated storage container with lid, and rope and pegs for drying.

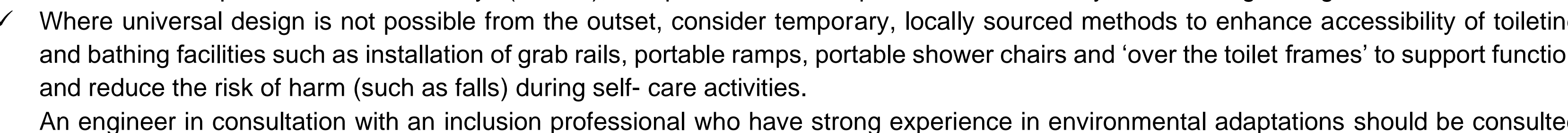
- ✓ Ensure the protection of persons with disabilities when using facilities from sexual exploitation and abuse by ensuring protection mechanisms are put in place with specific consideration of the needs of girls, boys, women and men with disabilities.
- ✓ Identify mentors with disabilities. Encourage mentors to use their leadership, skills and capacities to counter negative attitudes to disability and provide peer support. Consider introducing a buddy system for adolescents and youth with and without disabilities.
- ✓ Consider promoting a community support person/care giver program. Where people in the community (including persons with disabilities who are independent) are provided basic training on supporting persons with various functional difficulties to engage with their ADLs and these care givers are compensated for their time though contextually relevant means. This support could include, accompanying a person with disabilities on public transport, supporting their food access or personal care activities. This would enhance access and independence for persons who do not have a care giver/support person available to them and could relieve carer stress for care givers who may be overloaded with tasks in the context of other household roles.

- ✓ Promote the inclusion of persons with disabilities and monitor their participation by assembling community committees which include female and males with various difficulties, including visual, hearing, communication, intellectual and/or cognitive and mobility difficulties. Recognising the evolving capacities of children and youth with disabilities, where possible and safe, include children and youths with disabilities and their care givers to ensure representation in these mechanisms. These committees can participate in monitoring of the rights of persons with disabilities, their concerns and raise complaints and feedback to camp management.

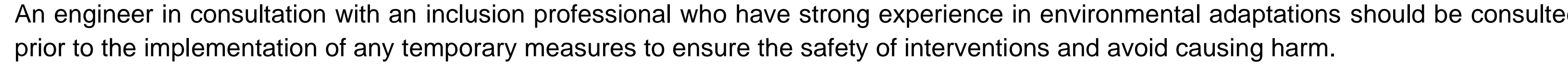
WASH - key recommendations on inclusion

Relates to 'must do actions'

- ✓ In line with the Sphere Standards (2018) which state that actors should 'consider access and use by age, sex and disability; people facing mobility barriers; people living with HIV; people with incontinence; and sexual or gender minorities; and should also 'locate any communal toilets close enough to households to enable safe access, and distant enough so that households are not stigmatised by proximity to toilets'.[21] Ensure water, sanitation and hygiene facilities are located within 25 metres of persons with significant functional difficulty and that at least 1 toilet in every 5, and 1 bathing facility in every 5 are designed in alignment with the universal design principles. This includes, at a minimum, ramp access, wide doorways (>90cm), adequate circulation space inside the facility, safe seating, and grab rails.



- ✓ Where universal design is not possible from the outset, consider temporary, locally sourced methods to enhance accessibility of toileting and bathing facilities such as installation of grab rails, portable ramps, portable shower chairs and 'over the toilet frames' to support function and reduce the risk of harm (such as falls) during self- care activities.



An engineer in consultation with an inclusion professional who have strong experience in environmental adaptations should be consulted prior to the implementation of any temporary measures to ensure the safety of interventions and avoid causing harm.

- ✓ Consider the distribution of commodes (portable toilets) and bed pans for people who cannot reach or use toileting facilities

- ✓ Consider the viability of training a smaller group of senior staff on basic environmental adaptations of WASH facilities and include persons with disabilities in this as experts.

- ✓ Identify the best distribution modalities for persons with disabilities. Options include accessible distribution sites, door-to-door delivery, a buddy system with other beneficiaries, sponsored transport, priority lines, etc.

- ✓ Provide additional hygiene supplies such as wet wipes, adult diapers, extra clothes, absorbent cotton material, disposable or reusable pads, washable leakproof mattress protector, second bucket, additional soap and moisturising lotion for persons with difficulties toileting and who are at risk of skin deterioration in their current dwelling.

- ✓ Women with disabilities may need access to flexible and diverse menstrual hygiene management materials. Adapt menstrual hygiene materials to meet their requirements. Consider supplying absorbent cotton pads, disposable or reusable sanitary pads, underwear, soap, a dedicated storage container with lid, and rope and pegs for drying.

- ✓ Ensure the protection of persons with disabilities when using facilities from sexual exploitation and abuse by ensuring protection mechanisms are put in place with specific consideration of the needs of girls, boys, women and men with disabilities.

[21] SPHERE (2018). The SPHERE handbook, 2018

Shelter and NFI - key recommendations on inclusion

Relates to 'must do actions'

- ✓ Identify the best distribution modalities for persons with disabilities. Options include accessible distribution sites, door-to-door delivery, a buddy system with other beneficiaries, sponsored transport, priority lines, etc.

  Remove

- ✓ Provide additional hygiene supplies such as wet wipes, adult diapers, extra clothes, absorbent cotton material, disposable or reusable pads, washable leakproof mattress protector, second bucket, additional soap and moisturising lotion for persons with difficulties toileting and who are at risk of skin deterioration in their current dwelling.

  Remove

- ✓ Women with disabilities may need access to flexible and diverse menstrual hygiene management materials. Adapt menstrual hygiene materials to meet their requirement. Consider supplying absorbent cotton pads, disposable or reusable sanitary pads, underwear, soap, a dedicated storage container with lid, and rope and pegs for drying.

  Remove

- ✓ Explore local solutions to reduce sleep difficulties, such as cots or mattresses on a locally built frame for persons with difficulties moving from the floor to standing/wheelchair and for persons who have health conditions impacted by sleeping at ground level.

  Remove

- ✓ Ensure that living space is accessible for persons with disabilities and those living with them. Persons with disabilities, particularly those with intellectual and psychosocial disabilities, may need additional space.

  Remove

- ✓ Ensure that camp design does not create accessibility barriers for persons with disabilities and promotes participation without increasing stigma. Consider width of walkways, ground surfaces and visual and communication cues and consult persons with disabilities for guidance on these issues.

  Remove Promote

CCCM, includes site planning - key recommendations on inclusion

Relates to 'must do actions'

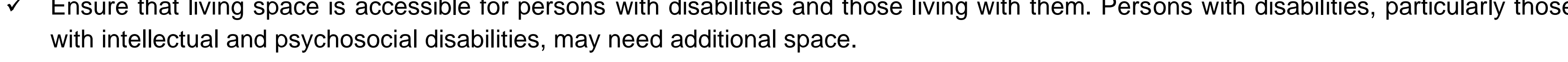
- ✓ In line with the Sphere Standards (2018) which state that actors should 'consider access and use by age, sex and disability; people facing mobility barriers; people living with HIV; people with incontinence; and sexual or gender minorities; and should also 'locate any communal toilets close enough to households to enable safe access, and distant enough so that households are not stigmatised by proximity to toilets'.[22] Ensure water, sanitation and hygiene facilities are located within 25 metres of persons with significant functional difficulty and that at least 1 toilet in every 5, and 1 bathing facility in every 5 are designed in alignment with the universal design principles. This includes, at a minimum, ramp access, wide doorways (>90cm), circulation space inside the facility, safe seating, and grab rails.

Remove

- ✓ Where universal design is not possible from the outset, consider temporary, locally sourced methods to enhance accessibility of facilities such as installation of grab rails, portable ramps, portable shower chairs and 'over the toilet frames' to support function and reduce the risk of harm (such as falls) during self- care activities.
  An engineer in consultation with an inclusion professional who have strong experience in environmental adaptations should be consulted prior to the implementation of any temporary measures to ensure the safety of interventions and avoid causing harm.

Remove

- ✓ Ensure that living space is accessible for persons with disabilities and those living with them. Persons with disabilities, particularly those with intellectual and psychosocial disabilities, may need additional space.



Remove

- ✓ Ensure that camp design does not create accessibility barriers for persons with disabilities and promotes participation without increasing stigma. Consider width of walkways, ground surfaces and visual and communication cues.

Remove

- ✓ Explore local solutions to reduce sleep difficulties, such as cots or mattresses on a locally built frame for persons with difficulties moving from the floor to standing/wheelchair and for persons who have health conditions impacted by sleeping at ground level.

Remove

- ✓ Ensure the protection of persons with disabilities when using facilities from sexual exploitation and abuse by ensuring protection mechanisms are put in place with specific consideration of the needs of girls, boys, women and men with disabilities.

Remove

- ✓ Promote the inclusion of persons with disabilities and monitor their participation by assembling community committees which include female and males with various difficulties, including visual, hearing, communication, intellectual and/or cognitive and mobility difficulties. Recognising the evolving capacities of children and youth with disabilities, where possible and safe, include children and youths with disabilities and their care givers to ensure representation in these mechanisms. These committees can participate in monitoring of the rights of persons with disabilities, their concerns and raise complaints and feedback to camp management.

Remove

Promote

Empower

[22] SPHERE (2018). The SPHERE handbook, 2018

Health - key recommendations on inclusion

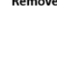
Relates to 'must do actions'

- ✓ When ill with COVID19, persons with disabilities may face additional barriers in seeking health care and also experience discrimination and negligence by health care personnel. Therefore, persons with disabilities in need of health services due to COVID-19 should not be deprioritized or denied treatment on the basis of disability.[23]

- ✓ Informed consent to health care and other services should always be obtained from all persons with disabilities regardless of the type of impairment. Various communication methods should be utilised to enable this.

- ✓ Persons with disabilities should be enabled to exercise maximum participation in decision making and their treatment and should be supported to communicate their needs while under treatment on an equal basis with others.

- ✓ All rehabilitation actors specifically, should ensure the availability of functional rehabilitation services for persons with disabilities that takes a holistic approach to rehabilitation in line with the domains of the International Classification of Functioning, Disability and Health (WHO, 2001).[24] This includes promoting functional independence in all personal, domestic and community activities of daily living through therapy, including assistive device provision.



- ✓ All rehabilitation actors should consider the functional difficulties of persons with disabilities in their home residence and address these during the therapeutic process, such as bathing, toileting, functional transfers (toilet, bed, chair), feeding and contextualised community mobility.

- ✓ Consider at a minimum, training for key staff in core Occupational Therapy assessment and intervention skills to promote the functional approach to rehabilitation and reduce the risk of functional decline and the onset of secondary health conditions, post discharge.

- ✓ All rehabilitation actors should consider expanding the assistive devices available to support activities that are not mobility related, such as built up cutlery and plate guards to promote independent feeding, and dressing aids to reduce dependence on a care giver and to promote better self-esteem. Accessories to support the use of specific devices e.g. pressure mattresses should also be provided and powered appropriately, using solar panels to ensure sustainability.

- ✓ Consider the distribution of commodes (portable toilets) and bed pans for people who cannot reach or use toileting facilities

- ✓ Explore local solutions to reduce sleep difficulties, such as cots or mattresses on a locally built frame for persons with difficulties moving from the floor to standing/wheelchair and for persons who have health conditions impacted by sleeping at ground level.

- ✓ Ensure referrals of persons with disabilities to required services such as (but not limited to) MHPSS, child protection case management and GBV services. Promote ongoing coordination with relevant protection actors to ensure holistic management and diverse needs are met.

[23] Syria Protection Cluster (Turkey) (2020). A brief guidance note: A disability inclusive COVID-19 response

[24] WHO (2001). International Classification of Functioning Disability and Health. Retrieved from: https://apps.who.int/iris/bitstream/handle/10665/4 2407/9241545429.pdf

Food security and Nutrition – key recommendations on inclusion

Relates to 'must do actions'

- ✓ Consider assisted eating and dietary requirements, and the nutritional quality of foods, including processed foods (proteins and other nutrients).

Remove

- ✓ Identify the types of food required (such as liquid foods) and adapt the size and format of food packages accordingly.

Remove

- ✓ Explore the viability of providing food processors, which can be powered by solar panels, and are available in northwest Syria to enable individuals to alter the texture of food themselves.

Remove

- ✓ Develop a community approach. Identify staff and where possible, community members, who will support persons with disabilities to access food rations (on site and via outreach). Provide reasonable accommodations[vi]; include assistance with transport, and childcare for parents of children with disabilities and for parents with disabilities.

Remove

Empower

Annex A. – Detailed methodology

Description of the methodology

In order to collect the necessary data, key informant interviews (KIIs) were conducted over the phone in Arabic by humanitarian staff who have a background in disability and inclusion. For those who have hearing and communication difficulties, a support person was present to support the interaction over the phone and often video call was used.

The KII's were conducted during the time of severe restrictions on movements to staff and beneficiaries due to COVID-19 related safety measures. A mixed purposive sampling method[vii] (a mixture of typical case sampling and criterion sampling[viii]) was utilised to select participants by drawing on recent health service databases. Inclusion criterion for participants was defined as having significant functional difficulty with one or more areas of daily functioning congruent with the Washington Group short set domains of functioning which are: communication, hearing, cognition, self-care, mobility and vision. Researchers aimed to ensure a diverse and consistent age, difficulty type and gender spread amongst participants in order to understand how the intersectionality of these, impacts experiences in this setting. Once a list of 100 potential participants was identified, staff began to call participants, explain the purpose of the research and gain consent to be interviewed. As a result of this process, 71 people (accompanied by care givers where relevant) consented to be interviewed and their responses were captured and analysed.

Analysis framework

It is understood that for persons with disabilities common barriers exist which can impede engagement in essential activities, particularly in humanitarian contexts. These include attitudinal barriers, physical environmental barriers and institutional barriers.

Persons with disabilities therefore are faced with increased difficulties in carrying out their Activities of Daily living (ADLS). ADLs describe both basic and complex activities that humans typically participate in to function and engage with their environments. These include, self-care/personal activities of daily living (PADLs), domestic activities of daily living (DADLs) and community activities of daily living (CADLs). PADLs include, toileting, bathing, dressing, grooming, eating/feeding and sleeping; DADLs include, food preparation, home environment maintenance and others; and CADLs include, using public/private transport, securing supplies and engagement with the community. Barriers to engagement in these ADLs individually and combined, can either facilitate or impede on persons with disabilities' access and participation in humanitarian distributions and services.

The Canadian Model of Occupational Performance and Engagement (CMOP-E) was used as an analytical framework to conduct a thematic analysis of the translated KII scripts. Where it was most useful and possible to do so, key themed responses were also quantified for later practical application. The CMOP-E is an occupational performance framework designed to understand the contributing factors which influence how an individual performs daily activities.[25] This framework enabled researchers to understand the barriers persons with disabilities living in northwest Syria experience when engaging in their Activities of daily living (ADLs) in line with the UNCRPD aligned, human rights model of disability and consequently the barriers they experience within the humanitarian response.[26]

Consent procedures

All participants were beneficiaries of humanitarian health services in the northwest of Syria. All beneficiaries who were short listed for potential inclusion in the study had previously consented to being contacted by the implementing organisation by phone. Given the physical movement and social distancing restrictions in place at the time, face to face consent procedures and signing of consent forms was not possible. Therefore, the right to refuse to participate in the KII, the right to withdraw from the KII at any time without consequences and the right to complete confidentiality and anonymity was explained and agreed on over the phone.

Limitations

Best practice in qualitative research indicates that KII's are conducted face to face in order to be able to gauge body language which further contextualises the participants' responses. Therefore, the inability to conduct KII's face to face was a major limitation and has likely impacted the rigor (validity and reliability) of the data. Further to this, for people with hearing and communication difficulties, although they were supported to participate, due to practical limitations, it's possible that their full views were not captured.

[25] Townsend, E., & Polatajko, H. (2007). Enabling occupation II: Advancing an occupational therapy vision for health, well-being, & justice through occupation. Ottawa: CAOT Publishers.

[26] Ibid

Additionally, the lead researcher was unable to conduct the KII's directly, due to the fact that this person does not speak Arabic. Staff who conducted the interviews, although fluent in Arabic and possessing a background in disability and inclusion, are not experts in conducting KII's and therefore this may also have impacted the rigor of the data. Further, the need for the transcripts to be translated from Arabic into English, again, means that the quality of the data may have been somewhat compromised.

Finally, the fact that KII's were administered by humanitarian staff may have impacted the quality of answers, particularly with regards to questions related to barriers to engagement with humanitarian organisations, as respondents may not have felt as they could be totally honest on these topics due to fear of judgment or reprisal, despite assurances that there was no danger of this.

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[i] Barriers are factors in a person's environment that hamper participation and create disability. For persons with disabilities, they limit access to and inclusion in society. Barriers may be attitudinal, environmental or institutional.

- Attitudinal barriers are negative attitudes that may be rooted in cultural or religious beliefs, hatred, unequal distribution of power, discrimination, prejudice, ignorance, stigma and bias, among other reasons. Family members or people in the close network of persons with disabilities may also face 'discrimination by association'. Attitudinal barriers are at the root of discrimination and exclusion.
- Environmental barriers include physical obstacles in the natural or built environment that "prevent access and affect opportunities for participation", and inaccessible communication systems. The latter do not allow persons with disabilities to access information or knowledge and thereby restrict their opportunities to participate. Lack of services or problems with service delivery are also environmental barriers.
- Institutional barriers include laws, policies, strategies or institutionalized practices that discriminate against persons with disabilities or prevent them from participating in society.

[ii] Universal design is the design of buildings, products or environments to make them accessible to all people, regardless of age, disability or other factors.

[iii] AAC: There are two types of aided systems—basic and high-tech. A pen and paper is a basic aided system. Pointing to letters, words, or pictures on a board is a basic aided system. Touching letters or pictures on a computer screen that speaks for you is a high-tech aided system.

[iv] A portable commode chair is a portable toilet that can be transported from one place to another. The portable commode chair is lightweight and relatively easy to move around.

[v] An over toilet frame is a useful aid which makes getting on and off the toilet both easier and safer. It provides a raised toilet seat height and armrests which are an alternative to rails. The over toilet frame has four legs of adjustable height, a plastic toilet seat and two armrests.

[vi] "Reasonable accommodation" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms;

[vii] The main objective of a purposive sample is to identify and select information rich cases related to the phenomenon of interest which in qualitative research, implies the best methodology to accurately describe experiences of a group.

[viii] Criterion sampling involves the identification of particular criterion of importance, articulation of these criterion, and systematic review and study of cases that meet the criterion.