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Working Document

Disability Task Force Guidelines

For prioritisation of disability-specific services for refugees and other vulnerable populations in Jordan

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About this document

This document was developed by the Disability Task Force (DTF) as technical guidance for humanitarian organisations providing services for refugees and vulnerable host populations with disabilities in camp and non-camp settings in Jordan.

It highlights areas of intervention necessary for a holistic scope of *specialized* health and education services, which the DTF will use to identify gaps in order to improve the quality and coverage of specialised disability services in the humanitarian response in Jordan.

This document provides guidance to assist humanitarian organisations to make sound programmatic decisions that ensure that where funds are limited resources are prioritised for interventions that are likely to have the greatest impact. It thus provides a set of minimum standards for planning, implementation, monitoring and evaluation of specialised disability services in Jordan.

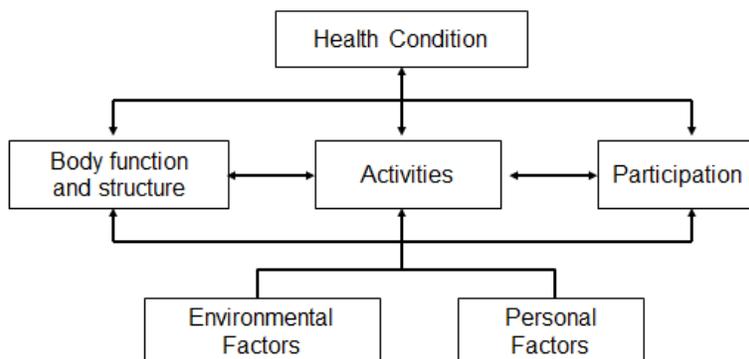
Guidance in this document is evidence based and/or in line with internationally recognised guidelines for disability specific services in resource-limited settings and/or contexts of displacement, where such guidance or evidence exists. In absence of pre-existing guidance or evidence, the recommendations in this document were developed in consultation with agencies working in the field of disability in Jordan.¹

This document is a working document and will be revised on a continuous basis as new guidance and evidence pertaining to disability specific services emerges. The DTF welcomes feedback on the guidelines, which can be sent to DTF co-chair Valerie Chamberger (UNHCR, schamber@unhcr.org) and Amira Khamis (HI, a.khamis@hi.org)

¹ Al-Hussein Society; Associazione Volontari per il Servizio Internazionale; British Council; Fundacion Promocion Social de la Cultura; Handicap International; Holy Land Institute for the Deaf; International Orthodox Christian Charities; Jordanian Hashemite Fund for Human Development; Mercy Corps; Movimiento por la Paz; Noor Hussein Foundation; Premiere Urgence Aide Medicale Internationale; Save the Children Jordan and the United Nations High Commissioner for Human Rights.

Definition and conceptual framework

“Persons with disabilities include those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others.” From Article 1, UN Convention on the Rights of Persons with Disabilities (CRPD).²



Interactions between components of the ICF³

Note on Inclusive Services:

While this document focuses exclusively on specialised disability services, the DTF recognises that in accordance with the CRPD that persons with disabilities have a right to access all mainstream services on an equal basis with non-disabled people. In order to ensure such equitable access, health and education service providers along with actors in all other areas of intervention (WASH, shelter, etc.) need to be sensitized, trained, and equipped to ensure access for all people regardless of disability or impairment.

² 2UN General Assembly, 2007. Convention on the Rights of Persons with Disabilities: resolution / adopted by the General Assembly, 24 January, A/RES/61/106, available at: <http://www.refworld.org/docid/45f973632.html> [accessed 29 November 2015].

³ WHO, 2002. Towards a Common Language for Functioning, Disability and Health: ICF. Geneva. <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf> [accessed 29 November 2015].

1. Coordination, Assessment, Monitoring and Evaluation

- Ensure protocols and procedures are in place to collect, analyse, interpret and use reliable data on persons with disabilities and their access to the necessary services as detailed in this document, including protocols for sharing confidential information in line with UNHCR's Policy on the Protection of Data of Persons of Concern.⁴
 - Provision of trainings on identification of people with disabilities and collection of disability-specific data during routine data collection;
 - UNHCR registration staff need training on disability identification during registration, using the UN Washington Group on Disability Statistics set of 6 questions.
- To ensure adequate assessment of needs in all sectors including identification of risks of/vulnerability to GBV, access to services and to avoid duplications, explore options for improving information on persons with disabilities including the use of a centralised database such as ProGres, ensuring that this is in compliance with UNHCR's Policy on the Protection of Data of Persons of Concern.
- Create mechanisms for sharing non-confidential aggregate data about disabilities with relevant government authorities, coordination groups and sectors.
- Establish clear referral mechanisms with feedback based on the most up-to-date map of available services, including clear information about the CP/SGBV SOPs and Referral Pathways.
- Continue to capture the views and needs of men, women, boys and girls with disabilities through participatory assessments such as UNHCR's annual Participatory Assessment as part of its Age, Gender, and Diversity Mainstreaming Strategy.⁵
- Ensure sharing of updated information on services available for PwD and referral pathways, with other working groups.

2. Primary and Secondary Prevention

Specific prevention activities are very important for the prevention of injury, impairment and disability. The following prevention initiatives should be prioritized:

- a. Injury prevention (awareness on fire safety in the home, road safety for children);
- b. Ensuring high coverage of routine vaccination in children and women of reproductive age;
- c. Provision of folic acid pre-conception and in the first three months of pregnancy;
- d. Access to emergency obstetric services and neonatal care to prevent and reduce sequelae of birth asphyxia and birth trauma;
- e. Screening for, and management of, treatable causes of hearing loss (e.g. chronic otitis media).
- f. Prevention of long term consequences of GBV (especially sexual violence and physical abuse) and violence against children.

⁴ UNHCR, 2015. Policy on the Protection of Data of Persons of Concern <http://www.refworld.org/protectionmanual.html> [accessed 29 November 2015].

⁵ UNHCR 2015b. UNHCR Tool for Participatory Assessment in Operations, <http://www.unhcr.org/pages/4a2698b86.html> [accessed 29 November 2015].

3. Tertiary Prevention

Specific medical and surgical interventions for people with certain impairments can significantly improve function and prevent or reduce deterioration. Therefore the following steps and services should be in place:

- a. Assessment of available specialized services (e.g. surgical and orthopaedic services) and establishment of referral mechanisms to these services.
- b. Surgery for preventable causes of visual impairment (e.g. cataract).
- c. Corrective surgery which can stabilise a person's condition, avoid deterioration, and/or improve level of function, such as talipes or spina bifida.
- d. Promote the early identification and referral to appropriate services of intellectual, physical and sensory impairment in infants and very young children.
- e. Reconstructive surgeries to be made available when they enhance mobility and function.
- f. Treatment of injuries (including from torture/abuse) to avoid permanent impairment
- g. Prevention of disabling effects of chronic non-communicable diseases especially diabetes and hypertension through access to medication, follow-up, and monitoring of disease control to reduce the risk of secondary complications such as peripheral vascular disease, cerebral vascular disease and diabetic neuropathy (as well as Rehabilitation, as detailed in section #7).
- h. Access to quality mental health services and management of depression, schizophrenia and bipolar disorder
- i. Pain management (pharmacological and non-pharmacological) and weight loss in persons with osteoarthritis (as well as Rehabilitation, as detailed in section #7)
- j. Avoidance and management of secondary complications such as pressure ulcers, urinary tract infections, respiratory tract infections, spasticity, deep vein thrombosis, and abnormal pain syndrome (among people with mobility impairments such as spinal cord injuries):
 - i. Provision of essential medications that will prevent complications and improve quality of life e.g. anticholinergics for abnormal movements, anti-spastic agents (muscle relaxants); stool softeners, anticonvulsants.
 - ii. Rehabilitation and provision of specialised hospital equipment (such as a pressure easing mattress), (see Rehabilitation section (#7)).
 - iii. Provision of essential medical items such as catheters (including intermittent catheters) and stoma bags for persons with certain kinds of paralysis and gastro intestinal conditions which are crucial for promoting independence and avoiding secondary infections and complications.
 - iv. Access to nursing care that includes patient (and caregiver) education and coaching about positioning, mobility, wound care, as well as bowel and bladder care.

4. Nutritional Support

- a. Take steps to address needs of people with disabilities with specific nutritional or food-related requirements (e.g. difficulty swallowing/chewing, gastroesophageal reflux). These include:
 - i. Technical support from a clinical dietician and/or speech-language therapist with expertise in adaptive feeding for people with specific disabilities, including provision of specific dietary and feeding plans, and speech therapy support to assist with swallowing difficulties;
 - ii. Provision of kitchen aids to assist with food preparation and feeding for those who need (spoons, straws, blenders).
- b. Identify tools and develop guidance on disability-specific screening for malnutrition.
- c. Train nutrition staff to monitor food and nutrient intake and assess nutrition status in persons with specific disabilities who are at risk of malnutrition.

5. Rehabilitation

Rehabilitation of people with disabilities is a process aimed at enabling them to reach and maintain their optimal physical, sensory, intellectual, psychological and social functional levels. Rehabilitation provides persons with disabilities with the tools they need to attain independence and self-determination. Access to rehabilitation services should be prioritized on the basis of impact on health, functioning and participation or reduction of vulnerability to protection risks, including prevention and response to GBV.

Interventions in the rehabilitation domain should include, as a minimum:

- Physical therapy sessions (facility and home-based) and follow-up, including community-based rehabilitation
- Occupational therapy (facility, community, and home-based)
- Provision of assistive devices
- Strengthened community based rehabilitation interventions, according to the WHO's guidelines on Community-Based Rehabilitation (WHO, 2012)⁶
- Train health workers to provide a training package on self-care to beneficiaries in hospitals before discharge
- Assistive communication devices, techniques and coaching and other assistive devices for people with communication difficulties
- Early intervention for children from ages 0 to 6 years, recognising that the earlier the intervention starts the greater the impact on improving outcomes (including occupational therapy, physiotherapy, speech therapy)
- Rehabilitation and self-care coaching to be provided to children in need of these services through educational facilities (whether mainstream or specialized schools)

⁶ WHO, 2002. Towards a Common Language for Functioning, Disability and Health: ICF. Geneva. <http://www.who.int/classifications/icf/training/icfbeginnersguide.pdf> [accessed 29 November 2015].

- Referral of women and girl with disabilities who are survivors of GBV to accessible safe spaces
- Facilitate social functioning and GBV risk mitigation for PwD

Criteria for targeting and prioritisation:

- a. Persons with disabilities with acute conditions and/or trauma requiring prompt intervention to avoid secondary complications
- b. Access to mobility and other aids should be based on the potential impact of the device (e.g. if this will prevent further deterioration of health and functioning prevent the further development of deformity, enhance mobility and promote comfort, enable access to education, facilitate independent living etc.)
- c. People with disabilities those conditions are expected to deteriorate when that deterioration is preventable by early intervention
- d. People with disabilities who already have a deformity which can be corrected, or to stop the progression of a deformity or to prevent other complications
- e. People with disabilities survivors of GBV

Key approaches for adaptive and assistive devices⁷ (replacement, repair, and maintenance)

Assistive devices are key tools in rehabilitation, as well as long-term home-based medical care.

- a. Annual projection of future needs for services to be based on updated prevalence data, waiting lists and coverage information.
- b. Assess how many, and what kind, of assistive devices need to be replaced and/or repaired and how many additional devices are required by people who did not have access to them before.
- c. Consider needs of both new and prior users of prosthetic and orthotic devices in relation to mobility outcomes. Determine what prosthetic and orthotic devices are essential to recovering the most optimal mobility for the recipient based on technical and technology standards.⁸
- d. Fitting and adaptation of mobility aids including wheelchairs is essential.
- e. Development and provision of a long-term policy for repair and maintenance of all assistive devices.

⁷ Any item, piece of equipment, or product, whether it is acquired commercially, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of individuals with disabilities

⁸ ISPO, 2006. *Prosthetics and Orthotics Programme Guide: Implementing P&O Services in Low-Income Settings*. <http://www.ispoint.org/guidelines-and-resources> [accessed 29 November 2015].

Minimum adaptive and assistance devices to be made available and prioritization of their distribution

a. Hearing aids and other assistive devices for persons with hearing impairments

- Hearing aids should be prioritised to children under 18 years of age with an average hearing impairment in the range of 31 to 80 dBHL in the better ear in the frequency range 500Hz to 4kHz, followed by adults with an average hearing impairment in the range 41 to 80 dBHL in the better ear in the same frequency range.⁹
 - For age 1-5 years provide body hearing aid.
 - For 5 years and above: normal hearing aids devices (behind ears).
- Provision of repair and maintenance of hearing aids to be included in programming.
- Follow-up and hearing tests recommended every 6 months.
- Ear-mould should be checked every 3-6 months depending on age; adults to be checked yearly.
- Batteries should be zinc air or rechargeable type. The availability of a reliable supply of batteries is an essential part of any hearing aid distribution activity.¹⁰
- Persons with profound hearing impairments may benefit from a cochlear implant. In Jordan these services are not accessible and children in need of these services may be referred for resettlement.

b. Visual aids (prescription glasses) as well as other devices for people with visual impairments i.e. low vision will be provided based on the level of visual impairment:

- i. Age 1-18 years (school aged children in/out of school) years to have priority.
- ii. Above 18years provision is on a case-by-case basis according to expected improvement in function. Priority to be given to myopia¹¹ (as opposed to presbyopia).
- iii. Albino cases (all ages).

c. Communication devices

- i. Provision of sign language interpretation at key service points.
- ii. Promote the teaching of sign language to children and adults who have not been taught sign language.
- iii. Establish SMS hotline and/or complaints handling mechanisms for people who are either hearing impaired or non-verbal.
- iv. Provision of communication boards (low maintenance, adapted to the context, not dependent on batteries/electrical supply, etc.)

⁹ WHO, 2004. *Guidelines for hearing aids and services for developing countries, Second Edition*. World Health Organisation, Prevention of Blindness and Deafness.

¹⁰ WHO, 2004. *Guidelines for hearing aids and services for developing countries, Second Edition*. World Health Organisation, Prevention of Blindness and Deafness.

¹¹ Myopia, known as "short-sightedness", as opposed to presbyopia, known as "long-sightedness" or the need for reading glasses.

d. Mobility aids

- i. Consider needs of new and old (previous) users of prosthetic and orthotic devices in relation to mobility outcomes.
- ii. Determine what prosthetic and orthotic devices are essential to be provided, repaired or replaced in order to recover or maintain optimal mobility for the recipient. Children should be given priority (ISPO, 2006).
- iii. Provision of fitting and adaptation of mobility aids including wheelchairs is essential. Design of mobility aids must be suitable for local conditions. Wheelchairs provided must be adapted to the individual needs of the user in order to avoid pressure ulcers and development of muscular contractures and orthopaedic deformities by making clear distinctions between different sizes of wheelchairs (S, M, L, adult, paediatrics, etc.) and providing protective seating, as needed (cushions, head support).
- iv. **The prioritization of specific mobility aids should be based on the following:**

Item	Criteria for prioritization
Standing frames	People who cannot stand at all independently and do not have any other devices and who can use the aid to improve their level of function.
Mobility aids (crutches, walker & gait trainer)	Cases who can walk with or without orthosis and need some support. For people who can use the aid to improve their level of function. People who lack strength and/or balance and cannot tolerate full weight bearing on both lower limbs.
Hospital wheelchair	People who require short-term mobility assistance, indoors and have adequate sensation.
Active Wheelchairs	For long-term use, for people who have enough upper limb strength to self-propel and have adequate trunk balance for sitting. Firstly, for people cannot walk at all, and second priority for cases which have difficulty in walking or cannot walk long distances.
High-support wheelchair (i.e. CP wheelchair)	People who cannot sit without support and/ or there is risk of developing deformity. People with poor head and trunk support and poor balance.
Supportive seating	People with poor head and trunk support and poor balance. People who cannot sit without trunk and/or head support and/ or there is risk of developing deformity.

Medical (anti-pressure) mattress	<p>Those who:</p> <ul style="list-style-type: none"> • Have pressure sores • Have no sensation in all or over a large area of skin • Are immobile • Are bed-ridden • Are comatose or semi-comatose • Have a history of pressure ulcers • Have severe diabetic neuropathy (presence of a combination of symptoms and signs of neuropathy include any two or more of the following: neuropathic symptoms “asleep numbness” (prickling or stabbing, burning or aching pain predominantly in the toes, feet, or legs; decreased distal sensation, or unequivocally decreased or absent ankle reflexes) • Have reduced mobility or immobility • Have a history of pressure ulcers • Have severe peripheral vascular disease (severe claudication with rest pain, pain at night, absent pulses)
Bed	Anyone who cannot stand up independently from floor level.
Toilet chairs	For people with limited mobility who cannot crouch down to use a floor-level (“Arabic”) toilet and whose homes do not have even one toilet high (“English”) toilet seat built in or who cannot transfer onto the toilet seat that is available.
Prosthetics	<p>People with lower limb amputations will be referred for assessment for a lower limb prosthesis.</p> <p>Upper limb prosthesis only to be considered when their provision is expected to provide noticeable improvement in level of function.</p>
Orthotics and splinting	To be further defined in the next six months.
<p>People with disabilities and their families need to be consulted and the needs they expressed will be taken into account into prioritization insofar as their priorities do not contradict clinical advice from medical and rehabilitation professionals consulted, and they fall within the above-mentioned criteria for prioritization.</p>	

6. Personal Assistance (including home-based care)

For persons **with functional limitations** requiring assistance with self-care and tasks of daily living the following interventions and activities should be made available, based on the following criteria to be used for the purposes of prioritisation:

Intervention/Activity	Criteria for prioritization (The criteria are listed in descending order of priority)
Identification of volunteer caregiver(s) for unaccompanied persons ¹²	<ol style="list-style-type: none"> 1. Newly injured persons (injury less than 1 year) 2. Minors (under 18 years) and elderly (over 60 years)¹³ 3. Women¹⁴ 4. Those with severe injuries such as spinal cord or traumatic brain injury from more than 1 year ago 5. All others
Ongoing training and information for primary caregivers	<ol style="list-style-type: none"> 1. Of newly injured persons, including spinal cord injuries (under 1 year). 2. Of children (under 18 years). 3. Of long-standing spinal cord and brain injuries (over 1 year). 4. Of elderly persons (over 60 years). 5. All others.
Material support ¹⁵ (hygiene materials including portable commodes, diapers, soap, and other NFIs)	<ol style="list-style-type: none"> 1. To promote healing and avoid infection post-surgery and associated with new injuries 2. To manage toileting (bladder/bowel care; faecal/urinary incontinence) 3. To avoid secondary infections and complications related to injury/impairment (good posture, skin care, etc.) 4. To prevent further impairments post injury
Information (and possible assistance) for organising / adapting / modifying living space	<ol style="list-style-type: none"> 1. Homes of people with new impairments (less than 1 year) 2. New arrivals (people recently arrived to the camp, or to their current home in last 6 months) 3. Further prioritisation based on severity of impairments
Home visits by medical / para-medical professionals in order to provide nursing and/or rehabilitation care	<ol style="list-style-type: none"> 1. People are unaccompanied and who cannot leave their homes due to being bed-ridden and/or immobile and/or living in an inaccessible home and/or facing protection concerns or threats

¹² Because they would have the least coping skills

¹³ Due to protection concerns

¹⁴ Due to protection concerns and more residential services being available for men than women

¹⁵ Further criteria needs to be determined following more research to establish an evidence-based prioritization of needs for specific materials/supplies

	2. People who cannot leave their homes due to being bed-ridden and/or immobile and/or living in an inaccessible home, even if accompanied by a caregiver
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7. Psychosocial Support

Intervention/Activity	Criteria for prioritization
Provision of psychosocial assessment for people with disabilities, elderly persons, and their caregivers including newly arrived refugees who meet these criteria.	<ol style="list-style-type: none"> 1. People assessed as vulnerable in the VAF process. 2. People who have been subject to physical, mental and/or emotional abuse, including sexual and/or gender based violence. 3. Persons with more severe intellectual and physical disability, immobile elderly or injured and their caregivers. 4. Child caregivers of adults with disabilities, as well as caregivers of older persons.
<p>Individualized, private PSS support sessions (via home visits) for persons with disabilities unable to leave their homes provided in accessible formats including sign language.</p> <p>Group psychosocial support sessions for families of persons with disabilities addressing specific issues of stigmatization and risks of marginalization.</p> <p>Peer support programme involving PWD in addressing issues of post-trauma among members of their community</p>	<ol style="list-style-type: none"> 1. Those experiencing high levels of isolation (stigma, severity of disability, family reluctance, vulnerability to SGBV). 2. War injuries or newly acquired disability. 3. Youth and adults with intellectual disabilities and their families 4. People severe physical disabilities, injuries or age-related impairments that prevent them from leaving the house, as well as their caregivers. 5. Unaccompanied children and older persons 6. Unaccompanied youth and adults
Sharing PSS minimum package information.	All health care providers including PTs and OTs

8. Protection:

Specific monitoring and attention paid to unaccompanied persons, single caregivers with disabilities, children with disabilities in alternate care (and those attending special schools/ institutions away from their families), and persons with severe or multiple disabilities or families with multiple persons with disabilities who are completely dependent on others for basic care and/or communication.

Ensure GBV information are available in all specialised centers and that specialized center staff are able to refer survivors with disabilities (confirmed or suspected cases) to existing GBV mechanisms. In this context, train case managers working with PWD on identifying risks and vulnerability and on referrals.

9. Education:

This section will be developed once a situation analysis of the educational needs and services provided to refugee and vulnerable host children with disabilities has been conducted.

UNHCR will:

- Conduct a desk review of existing data on children with disabilities (age, gender, type of disability, previous education if any, current situation regarding access to education);
- Map what services are provided by the Government of Jordan and private special education centers for Jordanian and refugee children with disabilities and compile any assessments of the quality of these services;
- Map existing special education services including referral pathways for children and training opportunities for teachers.

Annex: Data on persons with disabilities in Jordan

The World Report on Disability estimates that approximately 15% of the world's population has a moderate or severe disability.¹⁶ According to other research, this proportion likely increases among populations affected by conflict, even up to 20%.¹⁷

Quality data on persons with disabilities in Jordan is very limited due to a number of factors including humanitarian agencies' use of outdated tools for collecting data on disability and lack of consolidation of data between national actors. Tools that frame disability strictly as a health issue, ignore multiple other aspects of disability and do not allow for accurate identification of persons with disabilities.

According to a census from 2004, the Government of Jordan estimates that 1.23 percent of the population in Jordan have a disability, while the Higher Council of Affairs of Persons with Disabilities' estimate is 13 percent, not counting refugees. Only 2.36 % of refugees registered with UNHCR are identified as having a disability. Based on survey findings, Handicap International and HelpAge deem that 1 in 15 Syrian refugees has been injured as a result of the conflict.¹⁸ This survey estimates that across the region, 1 in 5 refugees has a physical, sensory or intellectual impairment. According to this survey, people with disabilities are twice as likely as the general refugee population to report psychological distress.

The inter-agency Disability Task Force in Jordan is working on improving identification of persons with disabilities by streamlining the Washington Group questions into various outreach mechanism used for analysis and targeting of humanitarian assistance to refugees in Jordan. This annex will be updated in due course to reflect the expected increase in numbers of identified cases of persons with disabilities once the Washington Group questions have been operationalised.

¹⁶ WHO (2011) World Report on Disability

¹⁷ Skinner , Marcus (2014) 'The Impact of Displacement on Disabled, Injured and Older Syrian Refugees', Forced Migration Review, issue 47, pp. 39-40.

¹⁸ Handicap International & HelpAge International (2014) Hidden Victims of the Syrian Crisis: Disabled, Injured and Older Refugees