USAID
FROM THE AMERICAN PEOPLE

POPULATION AND FAMILY HEALTH OFFICE

HEALTHCARE FOR PERSONS WITH DISABILITY IN JORDAN

OCTOBER, 2019

This publication was produced for review by the United States Agency for International Development by XL Associates Inc. under the Middle East Regional Platform (MERP) contract.

There can be little value in adopting a blanket, standardized approach to disability, because the individual experience of disability varies markedly by sex and according to other important factors such as age and also, of course, the nature of the disability.

Lina Abu-Habib
(Oxfam, 1997)

ACKNOWLEDGMENTS

This paper is one of a number of background documents that will inform the Office of Population and Family Health's (PFH) development of program activities for USAID/Jordan. The author wishes to thank Andrea Halverson, Deputy Director for her encouragement in developing this analysis, and Laura Itzkowitz for her review and input.

This paper has been drafted based on a desk review. While the author identified multiple sources of rich data, the document benefitted significantly from earlier work by Humanity and Inclusion (HI); UNICEF; Stephen Thompson's recent review of disability in Jordan for DFID, and Eric Carey *et al's*. research on vulnerability in Jordan for the World Food Program/REACH. The connection between disability and domestic violence was highlighted by Dr. Clare Ronalds, Clinical Lead on Domestic Violence in Manchester, England.

My thanks to Ruth Penfold for proof-reading of the document.

ACRONYMS

CBO	Community Based Organization
CPD	Continuing Professional Development
CRPD	[UN] Convention on the Rights of Persons with Disabilities
CwD	Children with Disability
C&YP	Children and Young People
DHS	Demographic Health Survey
DFID	Department for International Development (UK)
DPO	Disabled Persons Organization
FP/RH	Family Planning/Reproductive Health
HCP	Health Care Provider
HI	Humanity and Inclusion (formerly Handicap International)
HSS	Health Systems Strengthening
IP	Implementing Partner
JOD	Jordanian Dinar
MENA	Middle East and North Africa
MHPSS	Mental Health and Psychosocial Support
MNCH	Maternal, Newborn and Child Health
MOH	Ministry of Health
PFH	Population and Family Health [Office]
PwD	Persons with Disability
UNICEF	United Nations Children's Fund
WFP	World Food Program
WG	Washington Group [questions]
WHO	World Health Organization
YLD	Years Lived with Disability

EXECUTIVE SUMMARY

OVERVIEW OF DISABILITY

Core Issues: In Jordan and globally, there is a vicious circle that hinders action: a lack of data on persons with disabilities (PwD) prevents a reliable understanding of the challenges that PwD face. Without knowing the challenges, implementing partners (IPs) are ill-equipped to identify needs and collect appropriate data.

Research demonstrates that poverty is both a cause and an effect of disability (e.g. stunting in children is linked to repeated bouts of diarrhea) and families with a PwD on average have both lower income levels and higher healthcare costs. Breaking the poverty-disability cycle requires concerted efforts, for example to ensure parents of pre-school disabled children receive prompt advice and support to maximize the prospects of their child attending school.

Types of Disability: Disabilities fall into one of four categories:

- Physical (e.g. motor-related)
- Sensory (e.g. hearing or sight-related)
- Intellectual (e.g. learning-related)
- Mental (sometimes referred to as psychosocial) (e.g. depression, autistic spectrum disorders)

EPIDEMIOLOGY

Global: Between 1990 and 2017, the total burden of disability increased by 52%; around 80% is driven by non-communicable disease

Jordan: Using the UN-sponsored "Washington Group" of six standardized questions, the GOJ's 2015 Census found 11.2% of the population in Jordan (1,200,000 individuals) had a disability. Among refugee communities recent research found closer to 23% reported having a disability

CAUSES

Hearing loss is the most frequent birth defect in the world, and within the MENA region. Major causes of hearing loss are reported as consanguinity (blood marriage) and poor health related to poverty;

Poorer households are more likely to have children with disabilities and around 80% of children with disabilities live within households with a monthly income of 199 JOD or less

Insufficient food or a poorly balanced diet can leave infants and children vulnerable to specific conditions and infections that lead to physical, sensory or intellectual disabilities

Anemia in early childhood cause irreversible cognitive deficits

Diarrhea: Each episode of diarrhea in the first two years of life contributes to stunting, which is estimated to affect some 7.7% of children younger under 5 in Jordan

Partial Immunization can delay reaching developmental milestones, and results in avoidable secondary conditions

Domestic Abuse and Intimate Partner Violence perpetrated over long periods of time, results in elevated levels of fear and unsustainably-high cortisol levels. These cause physical disabilities related to the central nervous system symptoms; cardiac problems; gastrointestinal disorders; and viral infections.

CONSEQUENCES

The consequences of disability can be profound, but are not always inevitable

Child-related (heightened risk of malnutrition): For example, an infant with cleft palate may not be able to breastfeed or consume food effectively. Children with cerebral palsy may have difficulty chewing or swallowing. Certain conditions, such as cystic fibrosis, may impede nutrient absorption

Child-related (abuse): UNICEF estimate that 13.7% of Children with Disabilities (CwD) experience sexual violence, although the type of disability influences that. Overall, they are around 3.7 times more likely to suffer physical or sexual violence that children without disabilities;

Access to adequate education (Literacy): Around 35% of PWD are illiterate (40% female/32% male) compared with 11% of the general population in Jordan

Gender-related (FP): Young people with disabilities are often - incorrectly - assumed to be sexually inactive and therefore overlooked by sexual health programs

Access to Healthcare (Epilepsy): Around 70% of newly diagnosed children and adults with epilepsy can be successfully treated, and drugs withdrawn within two to five years

Poverty-related (Discrimination): Disability does not inevitably lead to poverty. It is at the point of discrimination that the cycle could be broken

RECOMMENDATIONS

Adopting a rights-based approach means that these are not intended as optional add-ons; rather they are the minimum that should be included to provide equitable access to health and healthcare. The main report includes 20 recommendations, set out under five themes.

Breaking the Cycle of Disability-Related Poverty:

- → Establish partnerships with local Disabled Peoples' Organizations (DPOs) and Community-Based Organizations (CBOs) that inform every stage of the program cycle
- → Continue support for the Joint Financing Agreement which is disproportionately beneficial to PwDs and families with PwDs
- → Prioritize efforts to ensure CwD are healthy-enough to attend school to break the link between disability and poverty

Capture and Use Disability-Related Data:

- → Build stakeholders' capacity to collect and disaggregate various data by disability, through the routine use of the Washington Group Questions

Planning for Inclusive Health:

- → Explicitly consider and design for inclusion into projects, (in much the same way that "gender" is routinely built in to programming)

Improvements for Health-Related Services:

- → Always ask "what changes are necessary to ensure this service is accessible for people with a (i) physical; (ii) sensory; (iii) intellectual and/or (iv) mental disability?
- → Where USAID is directly supporting CPD-course development, there should be a requirement to consider and reflect disability-awareness and inclusion
- → Explore maternal mental health provision for post-partum depression

Specific Adaptations for Child-health Services:

- → Identify children at risk through developmental screening to ensure they receive further assessment and interventions
- → Equitable responses will require a disproportionate and targeted approach to identifying children who have not received all their vaccinations
- → Increase awareness among HCPs and mothers of the risk of stunting from repeated bouts of diarrhea
- → Raise awareness among HCPs of the significantly higher risk of abuse of CwD. Work with MOH to develop a short set of questions and checks HCPs can use to identify abuse

1. INTRODUCTION

BACKGROUND

USAID's work in Jordan has spanned over five decades, resulting in many significant improvements in health. Much of the work has sought to improve reproductive, maternal, newborn and child health through a health system strengthening approach. Often that has been blind to disability-related issues, in much the same way that programs were characterized as gender-blind in previous decades.

This document offers a concise briefing on disability in the context of health in Jordan, and concludes with initial recommendations that identify both strategic and specific opportunities for the Population and Family Health (PFH) office to reduce discrimination and improve access to services. Naturally, the people most likely to offer the best input are people with disability themselves. This briefing in no way intends to undermine, circumvent or devalue their contribution. USAID/Jordan engages directly with Disabled Persons Organizations, and will do in late 2019 as part of its Country Development and Coordination Strategy process. This briefing is intended as a starting point on health-related issues for that and to be of guidance to implementing partners in the coming years.

2. OVERVIEW OF DISABILITY

DEFINITION

The United Nations Convention on the Rights of Persons with Disabilities (CRPD) uses the following definition: "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."[1]

CORE ISSUES

In Jordan and indeed globally, it is clear that there is a vicious circle that hinders action: if implementing partners (IPs) lack knowledge and tools to collect data on persons with disabilities, they will not understand the scale or scope of the issues PwD face. Without knowing the scale and scope, IPs will be ill-equipped to identify needs and implement inclusive programming.[2]

> *Disability does not inevitably lead to poverty. It is at the point of discrimination that the cycle could be broken. When disabled people are denied educational opportunities, then it is the lack of education, and not their disabilities that limits them.* *(Peters 2009)*

[1] United Nations (2006) Convention on the Rights of Persons with Disabilities. Article 1. New York. Available at: https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities/article-1-purpose.html

[2] Worley T (2017) Registering refugees with disabilities in refugee settings in Jordan. Available at: https://www.bond.org.uk/news/2017/06/registering-refugees-with-disabilities-in-refugee-settings-in-jordan

Poverty can be both a cause and an effect of disability. International and local research demonstrates that poverty is linked with causes of disability (e.g. stunting in children is linked to repeated bouts of diarrhea). Meanwhile families with a person with a disability on average have both lower income levels and higher healthcare costs.[3] Breaking the poverty-disability cycle requires concerted efforts, for example to ensure parents of pre-school disabled children receive prompt advice and support to maximize the prospects of their child attending school.

Humanity and Inclusion (HI) (formerly known as Handicap International) emphasize the need to work on child health and ensure children 6-12 years are able to get into school and helped to stay there. USAID partners play a crucial role in the ensuring appropriate education is available for PwD years 6-18, after which support to become economically-productive and an active part of civil society all help to improve integration, reduce stigma and enhance opportunity.

TYPES:

Disabilities fall into one of four categories:

- Physical (e.g. motor-related)
- Sensory (e.g. hearing or sight-related)
- Intellectual (e.g. learning-related)
- Mental (sometimes referred to as psychosocial) (e.g. depression, autistic spectrum disorders)

An individual may have one or more forms of disability. In recent years, global data shows that lifestyle-related causes, such as smoking, have overtaken other causes such as short-gestation for birth weight. Levels of disability in the population increase with age, peaking in working-age years and then declining due to disability-related premature deaths. In conflict-affected regions, there will be higher percentages affected by war-related physical injuries and post-traumatic stress disorder. Conflicts also have an indirect effect, increasing the levels of disability through for example, malnutrition which leads to anemia and affects the health of mothers and newborns in particular. Jordan is impacted by all of the above.

[3] Yeo R (2001) *Chronic Poverty and Disability*. ID 1754542, SSRN Scholarly Paper, 1 August. Rochester, NY: Social Science Research Network. Available at: https://papers.ssrn.com/abstract=1754542

3. EPIDEMIOLOGY:

GLOBAL:

- Globally, the total burden of disability increased by 52% between 1990 and 2017.
- The burden of disability is driven mainly by non-communicable diseases which caused 80% of disability in 2017.
- Leading risk factors for death and disability (all-ages) changed considerably between 1990 and 2017. In 1990, the leading risk factors for early death and disability were child wasting, short gestation for birth weight, and low birth weight for gestation. In 2017, the leadings risk factors were high blood pressure; smoking, and high blood sugar.[4]

JORDAN SPECIFIC:

Measuring rates of disability in Jordan is an inexact science. In recent years, much of the research into disability has been conducted with Syrian refugees, both in and outside of camps. A summary of Jordan-specific indicators can be found in Annexes A and B.

DISABILITY WITHIN THE JORDANIAN POPULATION:

- The 2015 Census found 11.2% of the population in Jordan (1,200,000 individuals) had a disability, based on the "short set" of Washington Group questions. Around 2.9% had "severe or absolute functional difficulties; this statistic is given greater prominence in the DOS findings;[5]
- Based on a sample size of 7,817 Syrian refugees outside of camps, UNHCR (2015) identified 16% who responded to a simple "yes/no" when asked if they had a disability or chronic illness;
- Other studies conducted between 2014 and 2018 found 7% of respondents had a disability (sample size 2,422 for non-Syrian, non-camp-based interviewees) (Nielsen 2017), while Care International found 1.5% of children and 5% of adults had a disability from a sample of 2,184 of whom 1,447 are Syrians (Care 2017).[6]

DISABILITY AMONG REFUGEES:

- The WFP/Reach Comprehensive Food Security and Vulnerability Assessment (2018) found 27% of households in host communities had a family member with a disability (based on the Washington Group six questions - see below);[7]
- Humanity and Inclusion's 2018 research found 22.9% of the 6,003 (age 2+)) Syrian refugees interviewed in Jordan reported having a disability. They also found disability prevalence to be higher in young males than females in age groups 2-34 years, and in older females than males in age groups 35 years and above.[8]

---

[4] Institute for Health Metrics and Evaluation (2018) *Findings from the Global Burden of Disease Study 2017*. Seattle, WA: IHME. Available at: http://www.healthdata.org/sites/default/files/files/policy_report/2019/GBD_2017_Booklet.pdf.

[5] Department of Statistics (DOS) (2015) *General Population and Housing Census 2015. Main Results*. Population and Housing Census. Amman, Jordan: Government of Jordan. Available at: http://www.dos.gov.jo/dos_home_e/main/population/census2015/Main_Result.pdf

[6] Asai Y, Barley H and Herzog J (2018) *Removing Barriers: The Path towards Inclusive Access (Jordan Report)*. Amman, Jordan: Humanity & Inclusion; iMMAP. Available at: https://data2.unhcr.org/en/documents/details/65892

[7] Carey E, Lindow O, Al Jawamees M, et al. (2019) *Jordan – Comprehensive Food Security and Vulnerability Assessment, 2018*. April. Amman, Jordan: WFP/REACH. Available at: http://www.reachresourcecentre.info/system/files/resource-documents/reach_jor_report_wfp_cfsva_may_2019.pdf

[8] HI & iMAPP (2018) *ibid*.

- Refugees with disabilities experience only temporary relief from functional difficulties where aid programs provide an initial assistive device (e.g. prostheses; spectacles; hearing aid) but are unable to cover costs related to repair or maintenance when devices are damaged or outgrown;[9]
- In 2013, a study of disability and chronic disease among Iraqi populations displaced in Jordan found 3.4% identified as disabled. The majority of Iraqi respondents in Jordan described healthcare as "unaffordable but accessible".[10]

WASHINGTON DATA COLLECTION GROUP:

Capturing data on disabilities is the first step to understanding priority issues that providers need to address to deliver inclusive services. Over the past two decades, a UN-led coalition of organizations has developed and refined a short-set of six questions that can be included in a wide variety of surveys. These are known as the "Washington Group" questions.[11] Their use enables tracking and correlations to be made to sharpen understanding for policy makers and service providers, as well as facilitating international comparisons.

A longer set of questions has also been developed that allows a more in-depth analysis of the different types of disability.

[9] Asai Y, Barley H and Herzog J (2018) *Removing Barriers: The Path towards Inclusive Access (Jordan Report)*. Amman, Jordan: Humanity & Inclusion; iMMAP. Available at: https://data2.unhcr.org/en/documents/details/65892

[10] Doocy S, Sirois A, Tileva M, et al. (2013) Chronic disease and disability among Iraqi populations displaced in Jordan and Syria. *The International Journal of Health Planning and Management* 28(1): e1–e12. DOI: 10.1002/hpm.2119

[11] Washington Group (n.d.) Washington Group Short Set of Disability Questions. In: *Washington Group on disability statistics*. Available at: http://www.washingtongroup-disability.com/washington-group-question-sets/short-set-of-disability-questions/

UNICEF Case Study: Asking the right questions - Uganda

- 1% of respondents responded "yes" to the 1991 census question "Is anyone who was in the household on census night disabled?"
- 4% of respondents responded "yes" to the 2002 census question "Does (name) have any difficulty in moving, seeing, hearing, speaking or learning, which has lasted or is expected to last 6 months or more?"
- 7% of respondents responded "yes" to the 2006 National Household Survey which asked "Do you have (serious) difficulty in moving, seeing, hearing, speaking or learning which has lasted or is expected to last 6 months or more?" = 7% National household survey 2006
- 20% of respondents identified a disability-related issues when asked 6 questions about disability for the 2006 DHS, including: "Does (name) have difficulty seeing, even if he/she is wearing glasses?"

UNICEF (2013)

4. CAUSES AND CONSEQUENCES OF DISABILITY

CAUSES:

Disease or illness caused the disability of one-in-three of the 22.9% of refugees identified by the Humanity and Inclusion's study.[12] Among minority populations (e.g. Bedouins and Palestinians), rates of disability tend to be higher than the general population, due to higher rates of poverty, malnutrition, violence, and lack of access to basic services.[13]

In 2005 the World Bank's Human Development Department reported that across MENA countries high rates of disabilities are caused by:

(i) Large numbers of individuals whose conditions could be mitigated with appropriate health and social interventions, and
(ii) Weaknesses in primary and secondary prevention mechanisms

Hearing loss is the most frequently occurring birth defect in the world and also in the MENA region. Major causes of congenital or early onset hearing loss are reported as blood marriage, mother's age, smoking and poor health related to poverty. (Hearing-loss at birth is around 6-7 times higher in Jordan than in the US.) [14]

Poverty: Poorer households are more likely to have children with disabilities (2-17) than households within higher income brackets. Around 80% of refugee children with disabilities in at least one domain reside within households with a monthly income of 199 JOD or less. This suggests a strong relationship between poverty and disability.[15]

Nutrition: Insufficient food or a poorly balanced diet short of certain vitamins and minerals (iodine, vitamin A, iron and zinc, for example) can leave infants and children vulnerable to specific conditions or a host of infections that can lead to physical, sensory or intellectual disabilities.

- Vitamin A deficiency, puts between 250,000 and 500,000 children at risk of blindness each year; oral supplementation costs just a few cents per child;
- Salt iodization remains the most cost-effective way of delivering iodine and preventing cognition damage in children in iodine-deficient areas;
- Anemia is one of the most prevalent causes of disability in the world. In early childhood anemia cause irreversible cognitive deficits and represents a higher risk of child mortality.[16]
- Diabetes affects around 13% of the Jordanian population and while a leading cause of death, it also leads to increased risks of disability. This includes heart disease, stroke, and epilepsy. Around 11% of adults referred to hospital for diabetic foot syndrome required amputations.[17]

---

[12] HI & iMAPP (2018) *Factsheet 1: Demographics and Disability. Disability Assessment among Syrian Refugees in Jordan and Lebanon*. HI & iMMAP. Available at: https://data2.unhcr.org/en/documents/download/65124

[13] Peters SJ (2009) *Review of marginalisation of people with disabilities in Lebanon, Syria and Jordan*. UNESCO. Available at: https://www.researchgate.net/profile/Susan_Peters11/publication/228876576_Review_of_marginalisation_of_people_with_disabilities_in_Lebanon_Syria_and_Jordan/links/563e515108ae34e98c4d9057.pdf

[14] Hakim G and Jaganjac N (2005) *A note on disability issues in the Middle East and North Africa*. 37275, 30 June. The World Bank. Available at: http://documents.worldbank.org/curated/en/912231468110689787/A-note-on-disability-issues-in-the-Middle-East-and-North-Africa

[15] HI & iMAPP (2018) *ibid.*

[16] Prieto-Patron A, Van der Horst K, Hutton ZV, et al. (2018) Association between Anaemia in Children 6 to 23 Months Old and Child, Mother, Household and Feeding Indicators. *Nutrients* 10(9). DOI: 10.3390/nu10091269

Diarrhea: A multi-country study showed that each episode of diarrhea in the first two years of life contributes to stunting, which is estimated to affect some 7.7% of children younger than 5 in Jordan.[18] The consequences of stunting, such as poor cognitive and educational performance, begin when children are very young but affect them through the rest of their lives.

Immunization: If children are only partially immunized, the results can include delays in reaching developmental milestones, avoidable secondary conditions and, at worst, preventable death.

Domestic Abuse and Intimate Partner Violence as a Cause of Disability: Domestic abuse is one of the largest contributors to disability globally. While the short-term consequences of physical violence result in acute injuries, domestic abuse perpetrated over long periods of time, results in elevated levels of fear and un-sustainably-high cortisol levels. These inadvertently cause physical illnesses through the build-up of fat tissue leading to weight gain.[19] Specific illnesses include recurring central nervous system symptoms (e.g. headaches); cardiac problems, such as hypertension and chest pain; gastrointestinal disorders; and viral infections. Physical abuse can also result in gynecological symptoms, such as vaginal bleeding or infection, fibroids, pelvic pain, and urinary tract infections.[20]

WHO have compiled global estimates of violence against women, and the related health effects. Currently there is no universally accepted dataset for non-physical domestic abuse (e.g. emotional; financial abuse etc.), which prohibits the collation of comparable statistics. However, issues associated with non-violent abuse include "fear"; "control" and psychological stress, which are also associated with physical violence perspective. The consequences these are set out in the table below.[21]

---

[17] Shatnawi NJ, Al-Zoubi NA, Hawamdeh HM, et al. (2018) Predictors of major lower limb amputation in type 2 diabetic patients referred for hospital care with diabetic foot syndrome. *Diabetes, Metabolic Syndrome and Obesity: Targets and Therapy* Volume 11: 313–319. DOI: 10.2147/DMSO.S165967.

[18] WHO-EM (2019) Eastern Mediterranean Region: framework for health information systems and core indicators for monitoring health situation and health system performance 2018. Cairo: WHO Regional Office for the Eastern Mediterranean. Available at: http://applications.emro.who.int/docs/EMROPUB_2018_EN_20620.pdf?ua=1

[19] Harvard Health Publishing (2018) Understanding the stress response. Available at: https://www.health.harvard.edu/staying-healthy/understanding-the-stress-response

[20] Campbell J, Jones AS, Dienemann J, et al. (2002) Intimate Partner Violence and Physical Health Consequences. *Archives of Internal Medicine* 162(10): 1157–1163. DOI: 10.1001/archinte.162.10.1157.

[21] García-Moreno C, Pallitto C, Devries K, et al. (2013) *Global and Regional Estimates of Violence against Women: Prevalence and Health Effects of Intimate Partner Violence and Non-Partner Sexual Violence*. Geneva, Switzerland: World Health Organization.

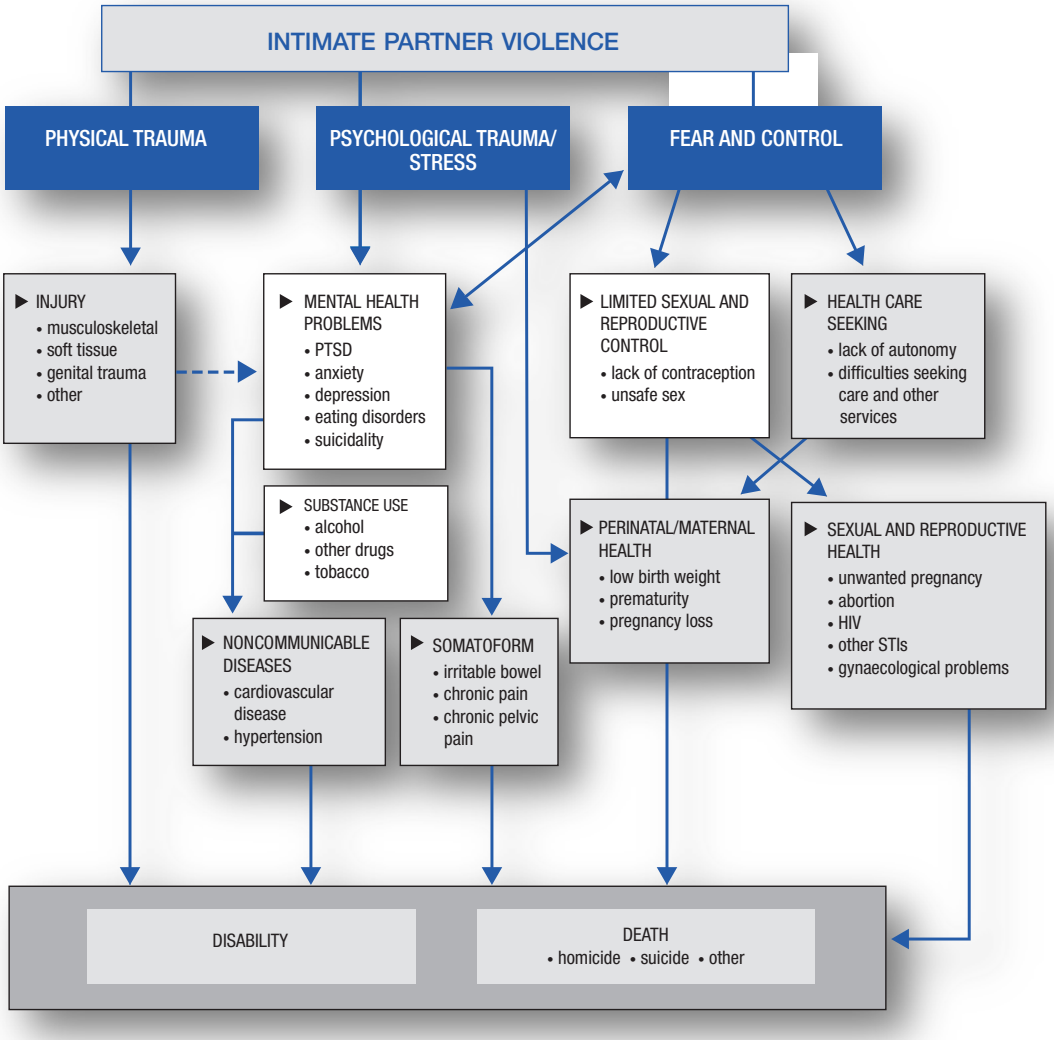


Figure 1 - García-Moreno C, Pallitto C, Devries K, et al. (2013) WHO

CULTURAL ISSUES:

A recent report on disability in Jordan for DFID (Thompson 2018) states that:

> "Jordan has a strong tradition of addressing disability issues and as a country has been internationally recognised for its efforts. It is often viewed as a regional leader on disability issues. However, continuing stigma surrounding disability results in people with certain types of disabilities being hidden away. Historically some Arab societies have displayed negative attitudes and beliefs towards people with disabilities, regarding them as a burden or shameful. Health-related stigma also exists, showing a lack of understanding about the abilities of people with disabilities. Recent evidence from Jordan indicates that more positive beliefs about disabilities are being adopted leading to more inclusive societies. Causes of disability are believed to be supernatural, faith-based and biomedical. The term disability in common parlance is only used to describe visible physical impairment".[22]

[22] Thompson S (2018) *The Current Situation of Persons with Disabilities in Jordan*. Brighton, UK: K4D Helpdesk Report: Institute of Development Studies. Available at: https://www.gov.uk/dfid-research-outputs/the-current-situation-of-persons-with-disabilities-in-jordan

The report also details the role of the King in establishing a new strategy for PwD in 2007, leading to the creation of the Higher Council for Persons with Disabilities. A new law included informed consent and the right to education, although Thompson notes that multiple exist laws remain inconsistent with the revised legislation.

CONSEQUENCES:

The consequences of disability can be profound, but are not always inevitable. Being mindful of PwD and ensuring programs actively consider how to first make services more inclusive and second, actively reach out to those most affected, can improve understanding of both the needs of beneficiaries and current barrier to access.

CHILD-RELATED:

- Children with disabilities are at heightened risk of malnutrition. For example, an infant with cleft palate may not be able to breastfeed or consume food effectively. Children with cerebral palsy may have difficulty chewing or swallowing. Certain conditions, such as cystic fibrosis, may impede nutrient absorption. Some infants and children with disabilities may need specific diets or increased calorie intake in order to maintain a healthy weight;[23]
- Anecdotal evidence points to disabled children being fed last, resulting in lack of nourishment
- One estimate in 2015 pointed to only 3% of children with a disability receiving a proper education. In 2014 it was estimated that 35% of PWD in Jordan are illiterate (40% female and 32% male), compared with 11% of the general population;[24]

Physiotherapy Enables Four-year Ali old to Attend School

Cerebral palsy results from being starved of oxygen at birth, but with the right support, individuals can overcome limitations others place on their ability.

"When we first came here, all I wanted was for my brother to stand up by himself. But it never crossed my mind that the physiotherapy sessions would make it possible for him to go to school one day,"

Humanity and Inclusion (n.d.) "My brother will be able to go to school now". https://humanity-inclusion.org.uk/en/news/my-brother-will-be-able-to-go-to-school-now

GENDER-RELATED:

- HI/IMMAP found significantly more females (34.6%) had disabilities related to illness or disease than males (24.7%);[25]
- UNICEF reports that girls and young women with disabilities are also less likely to get an education, receive vocational training or find employment than are boys with disabilities or girls without disabilities;[26]

[23] UNICEF (ed.) (2013) *Children with Disabilities*. The state of the world's children 2013. New York, NY: UNICEF. Available at: https://www.unicef.org/sowc2013/files/SWCR2013_ENG_Lo_res_24_Apr_2013.pdf

[24] Thompson S (2018) *ibid.*

[25] HI & iMAPP (2018) *ibid.*

[26] UNICEF (ed.) (2013) *ibid.*

- Young people with disabilities are often - incorrectly - assumed to be sexually inactive and therefore overlooked by sexual health programs;
- Children with disabilities (CwD) are around 3.7 times more likely to suffer physical or sexual violence that children without disabilities; UNICEF estimate 13.7% of CwD experience sexual violence, although the type of disability influences that. Children with mental or intellectual disabilities were 4.6 times more likely to be victims of sexual violence. [27]

ACCESS TO HEALTHCARE:

- Around 70% of newly diagnosed children and adults with epilepsy can be successfully treated, and drugs withdrawn within two to five years. UNICEF reports that up to three quarters of those who might benefit in low income countries lack access to treatment;
- Among Syrian refugees, households with disabilities were less likely to have access to required medical services at hospitals or clinics than households without disabilities (11.8% vs 7.2%, $P<0.05$);
- Access to medical services is especially an issue in Irbid. 17.0% of households with disabilities could not access medical services when needed, compared to 11.2% of households without disabilities. Barriers to healthcare included transportation, as cited by 38.1% households with disabilities;

SOCIAL PROTECTION:

- Jordan offers free Social Health Insurance to all people with disabilities yet in 2017 it was estimated that a third of Jordanians with disabilities were not covered. Also, despite many medical centres now being physically accessible with specially trained staff, challenges around transportation to the centres persist. Data from 2017 suggests that the Ministry for Social Development administers support to 12,000 people with disabilities, accounting for 12 percent of the National Aid Fund; [28]

INCLUSION AND DISCRIMINATION

- Disability does not inevitably lead to poverty. It is at the point of discrimination that the cycle could be broken;[29]
- Prejudice can be effectively reduced through interaction, and activities that bring together children with and without disabilities have been shown to foster more positive attitude;[30]
- Around 24% of men with a disability are employed in contrast to only 5% of women. The employment rate for PWD is approximately half what it is for those without a disability.[31] This can have a substantial impact on income. For example, those who have diabetes that require amputations, this is likely to directly affect their employability.

[27] UNICEF (ed.) (2013) *ibid.*

[28] Thompson S (2018) *ibid.*

[29] Peters SJ (2009) *ibid.*

[30] UNICEF (2013) *ibid*.

[31] Thompson S (2018) *ibid.*

5. RECOMMENDATIONS TO SUPPORT PERSONS WITH DISABILITY

The following are recommendations to improve the wellbeing of PwD using on a rights-based approach. These are therefore not intended as optional add-ons; rather they are the minimum that should be included to facilitate equitable improvements in health and access to health services.

BREAKING THE CYCLE OF DISABILITY-RELATED POVERTY

1. Establish partnerships with local Disabled Peoples' Organizations (DPOs) and Community-Based Organizations (CBOs) that inform every stage of the program cycle, to gain a stronger understanding of the true needs of persons with disabilities
2. Continue support for the Joint Financing Agreement to facilitate prompt access to healthcare among refugees, which is disproportionately beneficial to PwDs and families with PwDs
3. Ensuring CwD can be supported so that they are healthy-enough to attend school is the first and most fundamental step in breaking the link between disability and poverty;
4. Work with other USAID DOs to improve supportive, inclusive approaches for PwD in Jordan;

CAPTURE AND USE DISABILITY-RELATED DATA

5. Build stakeholders' capacity to collect and disaggregate various data by disability, through the routine use of the Washington Group Questions;
6. Identify people and households with disabilities who would most benefit from inclusion, through better data usage;
7. Explore whether access to anti-epilepsy medication is optimal and address through HSS approaches if not;

PLANNING FOR INCLUSIVE HEALTH

8. Explicitly consider and design for inclusion into projects, (in much the same way that "gender" is routinely built in to programming);
9. Budget for inclusion (e.g. consultation with DPOs; adaptations for SBC approaches);
10. Use advocacy and an enabling environment approach to ensure inclusion is part of the Journey to Self-Reliance, particularly through government-to-government mechanisms;

IMPROVEMENTS FOR HEALTH-RELATED SERVICES

11. Always ask "what changes are necessary to ensure this service is accessible for people with a (i) physical; (ii) sensory; (iii) intellectual and/or (iv) mental disability?
12. Reduce prejudice by ensuring group-activities are inclusive (e.g. ante-natal groups; breast-feeding support)
13. Explore how to improve maternal mental health, such as post-partum depression. (This is permissible using USAID funds, and is a feature of the forthcoming MOMENTUM award)
14. Consider developing prevention strategies that include identifying women who are at elevated risk of domestic abuse. This will require greater awareness among HCPs and could be incorporated into CPD programs;
15. Where USAID is directly supporting CPD-course development, there should be a requirement to consider and reflect disability-awareness and inclusion;
16. Work with DPOs to raise awareness among HCPs of the family planning needs of PwDs;

SPECIFIC ADAPTATIONS FOR CHILD-HEALTH SERVICES

17. Identify children at risk through developmental screening to ensure they receive further assessment and interventions;
18. For children born with a disability, such as a cleft palate, build care pathways that pro-actively support the child and family. Initially this could be achieved through a nutrition-focused approach;
19. Equitable responses will require a disproportionate and targeted approach to identifying children who have not received all their vaccinations. This could be enhanced through private sector engagement;
20. Increase awareness among HCPs and mothers of the risk of stunting from repeated bouts of diarrhea;
21. Raise awareness among HCPs of the significantly higher risk of abuse of CwD. Work with MOH to develop a short set of questions and checks HCPs can use to identify abuse;

ANNEX A: SUMMARY STATISTICS (JORDAN)

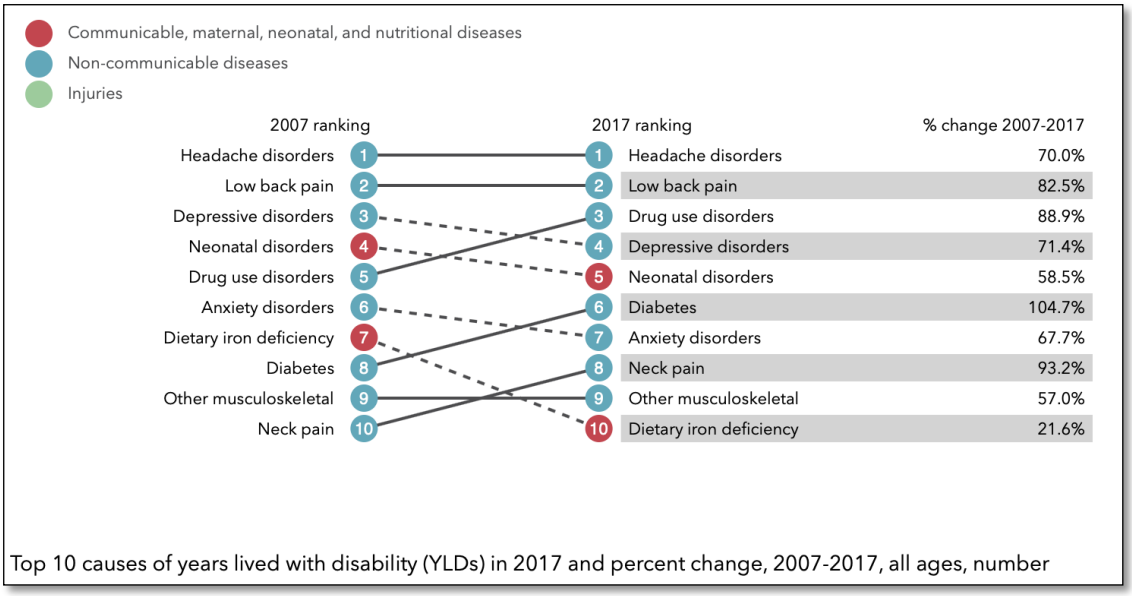
The following statistics were compiled in 2018 by Stephen Thompson (Institute of Development Studies) for DFID, as part of a wide-ranging paper on the current situation related to people with disabilities within Jordan.[32]

National disability prevalence	13%
Number of persons with a disability	1,100,000
Prevalence of Syrian refugees in Jordan with physical or intellectual needs	30%
Percentage of children with disabilities receiving education	3%
Percentage of persons with disabilities who are illiterate	35.3%
Estimated Syrian refugee children of school age in Jordan with a disability	10,000-15,000 children
Percentage of schools accommodating disabled students with an accessible latrine	11%
Employment rate of persons with disabilities	16.1%
Percent of persons with disabilities who are female	41%
Leading type of disability	Locomotor disability (17.3% of the total)
Percent of refugees in Jordan with a significant injury	8% (of which 90% were conflict-related)
Percent of refugees who had been injured and experience psychological distress	80%
Percentage of impairments of refugees in Jordan.	44.2% physical 42.5% sensory 13.4% intellectual
Percentage of impairments in child refugees in Jordan	36% physical 25% visual 19% mental
Percent of refugees had multiple impairments	20%

[32] Thompson S (2018) *ibid.*

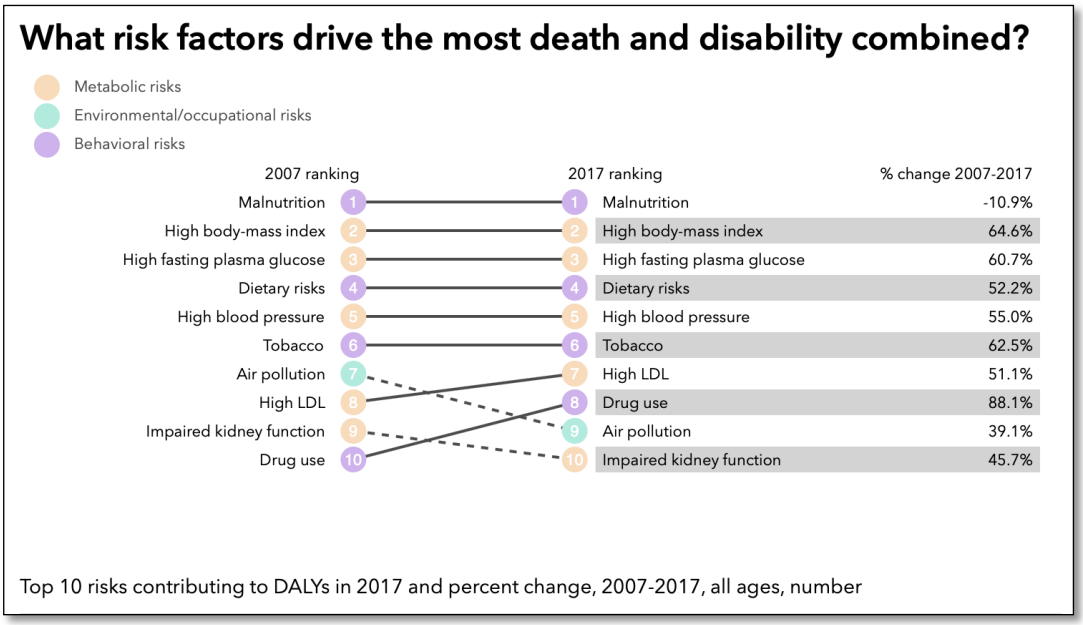
ANNEX B: JORDAN- SPECIFIC STATISTICS BASED ON THE INSTITUTE FOR HEALTH METRICS AND EVALUATION'S GLOBAL BURDEN OF DISEASE SURVEY (2017)

The Institute for Health Metrics report on the Global Burden of Disease includes estimates for disability-related data in Jordan. Although the coding of "communicable & MNCH" compared to "non-communicable" is debatable - for example when considering post-partum depression - the charts below demonstrate shifts in the patterns of the causes of years lived with disability.



Top 10 causes of years lived with disability (YLDs) in 2017 and percent change, 2007-2017, all ages, number

While it is clear that some progress has been made in reducing malnutrition as the leading factor behind death and disability in Jordan, evidently it remains the most pressing challenge.



Top 10 risks contributing to DALYs in 2017 and percent change, 2007-2017, all ages, number

ANNEX C: AGE-RELATED DATA BASED ON THE INSTITUTE FOR HEALTH METRICS AND EVALUATION'S GLOBAL BURDEN OF DISEASE SURVEY (2017)

Global data produced by the Institute for Health Metrics reveals how disability develops with age. report on the Global Burden of Disease includes estimates for disability-related data in Jordan. The very deep-red band related to "nutritional deficiencies" is particularly pronounced in childhood years, and demonstrates considerable scope for early interventions to reduce long-term impact.