

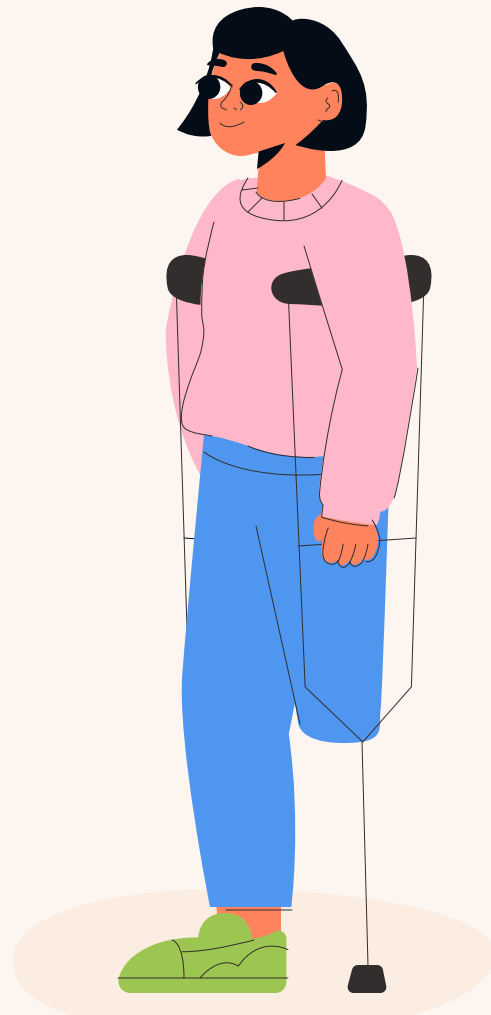
Persons with disabilities (PWD)

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2024



Objectives:

- To understand the definitions and concepts related to disabilities.
- To recognize the prevalence, causes and types of disabilities globally and in Jordan.
- To identify the public health challenges and interventions for PWDs.



Before We Start: The Etiquette of Inclusive Language:

- **Person-First Language:**

- Describe the person, not the disability.

- Example: "Person with a hearing impairment," not "deaf mute."

- **Avoid Negative or Outdated Terms:**

- Instead of: *Crippled, retarded, spastic.*

- Use:

- **Wheelchair user** instead of "confined to a wheelchair."

- **Person with a visual impairment** instead of "blind."

- **Person with cerebral palsy** instead of "spastic."

- **Relevance Matters:**

- Refer to a person's disability **only when it is relevant.**

- **Avoid Pity-Based Language:**

- Avoid terms or images that evoke **pity or guilt.**


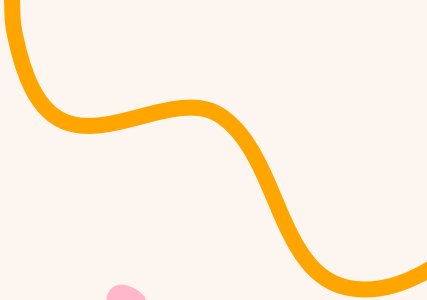


I CHOOSE NOT TO PLACE "DIS"
IN MY ABILITY





Introduction:

- **Global Impact:** 1.3 billion people, or **16%** of the world's population, have significant disabilities (**1 in 6 people**).
 - **Reduced Life Expectancy:** Some live up to **20 years** less than those without disabilities.
 - **Health Inequities:** PWDs face unequal access to healthcare and outcomes. 50% of disabled persons cannot afford health care.
 - **Health inequities arise from unfair conditions:** Stigma, discrimination, poverty, exclusion from education and jobs, and barriers in healthcare systems
 - 80% of all people with disabilities live in a ***developing country***
- 
- 







WHO's Definition of Disability Using the ICF Framework

- The International Classification of Functioning, Disability, and Health (ICF) by the WHO:

defines **disability** as: an umbrella term for impairments, activity limitations, and participation restrictions, emphasizing the interaction between an individual's health condition and their environment.

Convention on the Rights of Persons with Disabilities:

Disability is an evolving concept and “results from the interaction between persons with impairments and attitudinal and environmental barriers that hinders their full and effective participation in society on an equal basis with others”.





Medical vs Social model:

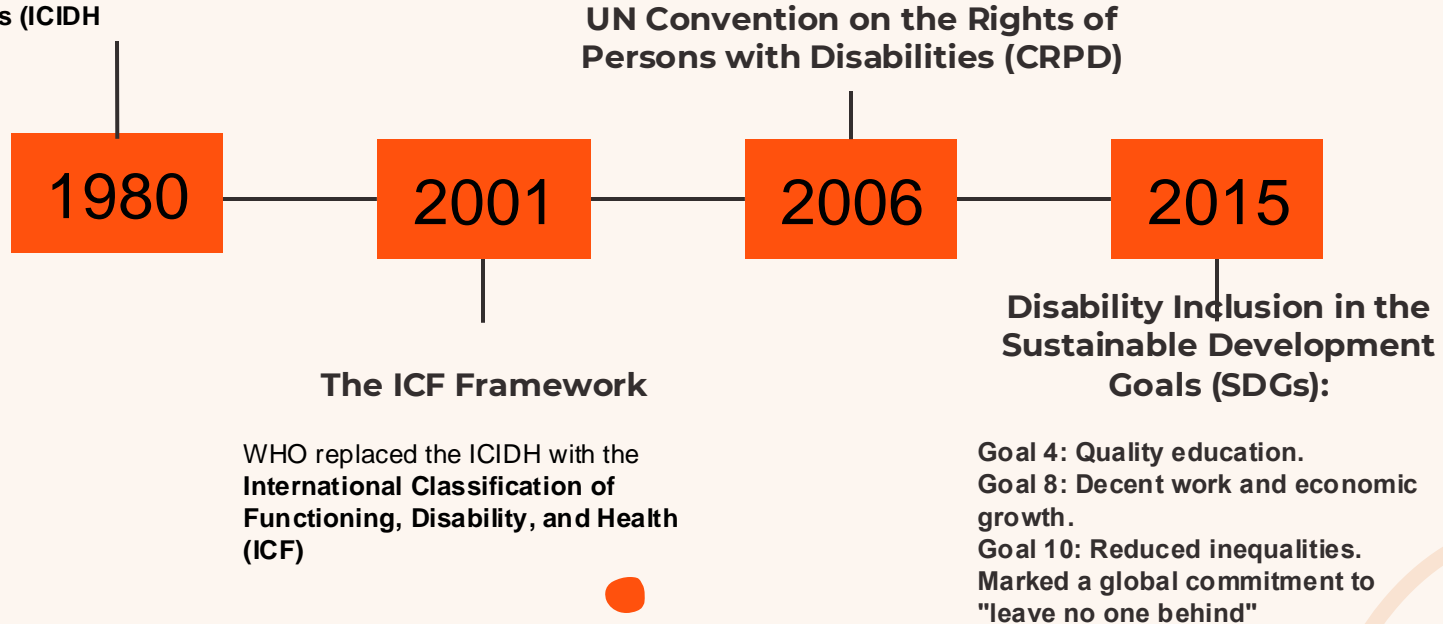
- Disability can be understood in two different ways: the **medical model** and the **social model**.
- The **medical model** sees disability as a problem caused by issues in the body or health. It focuses on treating or fixing these problems through medical care.
- The **social model** looks at disability as a problem created by society, such as barriers and unfair treatment. Instead of just trying to cure the person, this model focuses on changing society to remove barriers and create equal opportunities for everyone.



Timeline of PWD related models:

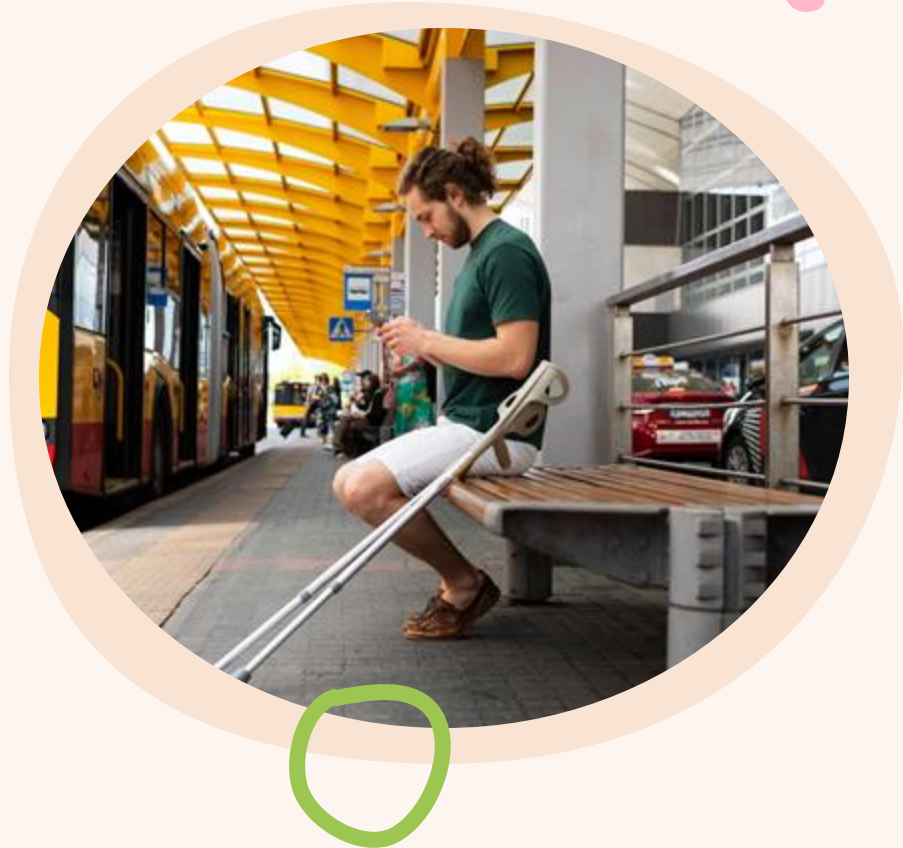
The Old Model – ICIDH :

Before the ICF, the WHO introduced the **International Classification of Impairments, Disabilities, and Handicaps (ICIDH)**



The Old Model – ICIDH:

- The ICIDH used the following terms:
 - **Impairment:** A physical or mental abnormality in body structure or function.
 - **Disability:** The resulting difficulty in performing tasks or activities.
 - **Handicap:** The social disadvantage arising from impairments or disabilities, restricting the person's fulfillment of roles.



To simplify,

- A person who is born blind (**the impairment**) is unable to read printed material, which is how most information is widely disseminated (**the disability**). If this person is prevented from attending school or applying for a job because of this impairment and disability, this is a **handicap**.



Why it became outdated!



The term "handicap" is stigmatizing.



It focused too much on the individual's limitations rather than addressing environmental and societal barriers.



Disability was viewed mainly as a medical condition rather than a whole interaction

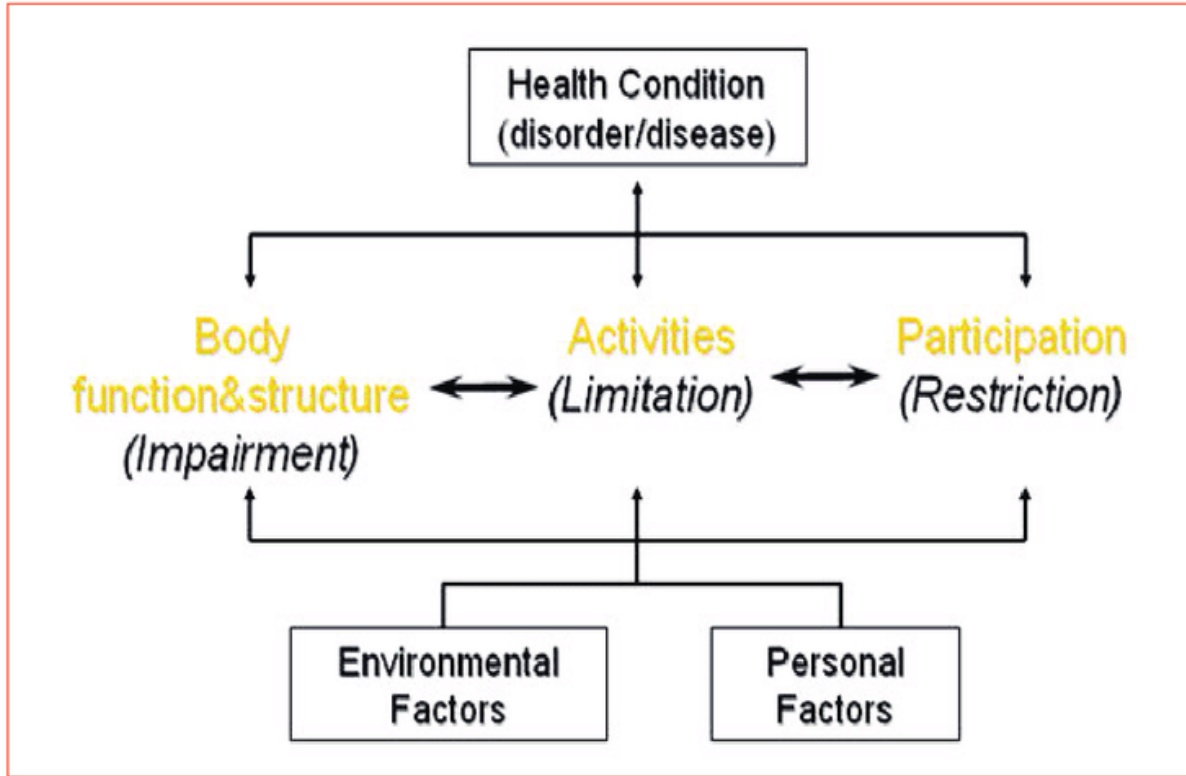
**The ICF
Framework -
Adopted in 2001**

ICF Focus:

Disability is viewed as the **interaction** between health conditions and **circumstances related factors** (environmental and personal factors).



Framework,



Framework,

•Health Condition:

- Diseases, disorders, or injuries (e.g., stroke, diabetes, spinal injury).

•Functioning and Disability:

•**Body Functions and Structures:**

- Body functions: Physiological or psychological processes (e.g., vision, memory).
- Body structures: Anatomical components (e.g., organs, limbs).
- Impairments: Problems or deviations in body functions/structures.

•Activities:

- Completing of tasks or actions (e.g., walking, eating).
- Activity Limitations: Difficulty in performing activities.

•Participation:

- Involvement in life situations (e.g., working, attending school).
- Participation Restrictions: Challenges in participating due to barriers.

•Related Factors:

•**Environmental Factors:**

- Social attitudes, physical environment, assistive technologies, and policies.

•**Personal Factors:**

- Age, gender, education, lifestyle, coping strategies.

Examples:

HEALTH CONDITION	IMPAIRMENT	ACTIVITY LIMITATION	PARTICIPATION RESTRICTION
Leprosy	Loss of sensation of extremities	Difficulties in grasping objects	Stigma of leprosy leads to unemployment
Panic Disorder	Anxiety	Not capable of going out alone	People's reactions lead to no social relationships
Vitiligo	Facial depigmentation	None	No participation in social relations due to fears of infection
Person who had a psychotic disorder and treated	None	None	No employment because of employer's judgment

Categories of Disability:

The main types of disabilities recognized globally:

- **Physical Disabilities:** Impairments affecting mobility or dexterity (e.g., spinal cord injuries, amputations, stroke, cerebral palsy).
- **Sensory Disabilities:** Impairments in vision or hearing (e.g., blindness, deafness, Language issues caused by hearing impairments).
- **Intellectual Disabilities:** Limitations in cognitive functioning, learning and adaptive behavior (e.g., Down syndrome, autism).



Categories of Disability:

- **Mental Health Disabilities:** Disorders affecting emotional, psychological, and social well-being (e.g., depression, anxiety).
- **Neurodevelopmental disabilities:** (ADHD, Dyslexia (Difficulty with reading, spelling, and decoding language), dyscalculia (difficulty with math) and dysgraphia (difficulty with writing), Autism Spectrum Disorder).
- **Multiple Disabilities:** A combination of two or more impairments (e.g., deaf-blindness).
- **Hidden Disabilities:** Conditions not immediately visible, such as epilepsy, diabetes, or chronic pain.

Anxiety Disorders

Dyslexia
As a child grows, dyslexia can often...

C O U
C _ _ _ T
Difficulty spelling simple words.

p q ? ? b d ? ?
Confusing letters with similar shapes.

Do words and sentences move around when you read?

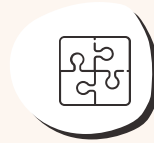
Causes of disability:



1. Genetic Causes:



2. Acquired Causes:



3. Environmental and Social Causes:



1. Genetic causes



- Disabilities that originate from inherited genetic mutations, chromosomal abnormalities, or spontaneous genetic errors. Typically present at birth (congenital conditions) but may show signs later in life.

Examples:

- **Down Syndrome:** (trisomy 21). Associated with intellectual disability, physical abnormalities, and increased risk of medical conditions.
- **Muscular Dystrophy:** Group of genetic disorders that cause progressive muscle weakness and degeneration. Duchenne Muscular Dystrophy is the most common and severe form.
- **Fragile X Syndrome:** Genetic condition linked to intellectual disability and behavioral challenges.
- **Cystic Fibrosis:** Genetic disorder affecting respiratory and digestive systems due to thick mucus production.
- **Hereditary Hearing Loss:** Mutations in genes (GJB2) lead to congenital or progressive hearing impairment.
- **sickle cell disease:** autosomal recessive

2. Acquired causes



Disabilities acquired through events or exposures that occur prenatal, perinatal, or post natal

A. Prenatal Causes: Factors affecting the fetus during pregnancy.

1. Maternal Infections:

TORCH Infections:

T: Toxoplasmosis.

O: Other (syphilis, Zika virus).

R: Rubella – causes hearing loss, congenital heart defects, and cataracts.

C: Cytomegalovirus (CMV) – leads to hearing loss and intellectual disabilities.

H: Herpes Simplex Virus – can cause brain damage and eye abnormalities and cognitive impairments.

Congenital Syphilis: Palmar/solar rash



**Rubella
Syndrome**

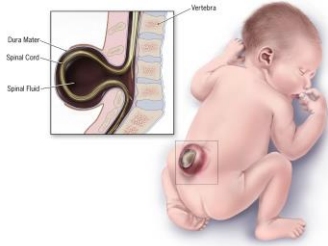


2. Acquired causes

FAS Facial Characteristics:

- small eye openings.....
- smooth philtrum.....
- thin upper lip.....

Spina Bifida (Open Defect)



2. Malnutrition: Insufficient folic acid increases the risk of neural tube defects (e.g., spina bifida).

3. Radiation Exposure Ionizing radiation can damage fetal cells, especially during organ formation.

4. Toxins and Substance Exposure:

- **Fetal Alcohol Syndrome** caused by alcohol consumption during pregnancy.
- **Smoking and drug use** can lead to low birth weight and developmental delays.
- **Teratogenic Drugs** Medications that interfere with fetal development, especially in the first trimester.



Malformations due to maternal ingestion of thalidomide (Schardein 1982 and Moore 1993).

Examples:

Thalidomide: Causes limb deformities (phocomelia).

Isotretinoin (Accutane): Leads to brain, heart, and facial deformities.

Anticonvulsants (e.g., valproic acid): Increases the risk of neural tube defects and developmental delays.



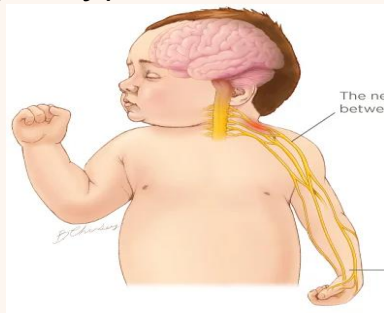
2. Acquired causes

B. Perinatal Causes: Events occurring around the time of delivery.

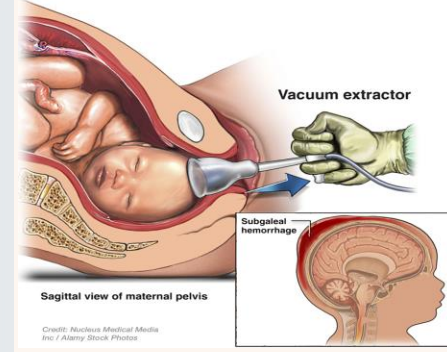
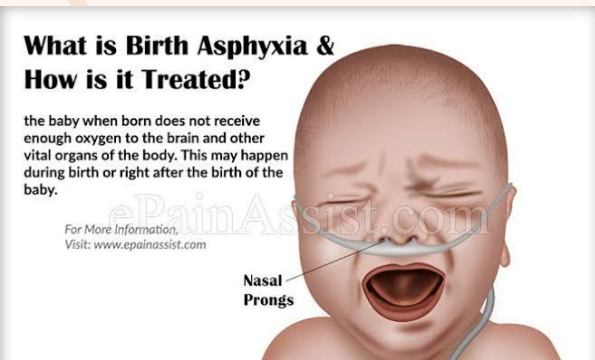
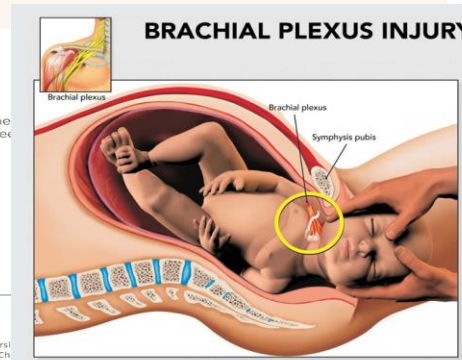
1. Birth Asphyxia: Lack of oxygen during delivery can lead to brain injury and conditions like cerebral palsy.

2. Premature Birth: Associated with underdeveloped organs and increased risk of learning disabilities and vision impairment (e.g., retinopathy of prematurity).

3. Traumatic Birth Injuries: Use of forceps or vacuum extraction can cause physical injuries, such as brachial plexus injuries (Erb's palsy).



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2. Acquired causes



C. Postnatal causes: Factors occurring after delivery during infancy or later in life.

1. Infectious Diseases:

- Meningitis: Can cause hearing loss, brain damage, or seizures.
- Polio: Leads to paralysis in severe cases.

2. Malnutrition: Deficiencies in essential nutrients like iodine or vitamin A can cause developmental delays or blindness.

3. Trauma and Accidents: Road traffic accidents leading to spinal cord injuries or traumatic brain injuries.

4. Chronic Illnesses: (diabetes or strokes) may lead to disabilities such as vision loss or hemiplegia. ●



INSPIRING STORY:

https://www.youtube.com/watch?v=675_pAYsG1

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Prevention Strategies

Primary, Secondary, and Tertiary Prevention

Primary Prevention:

Aims to prevent disabilities before they occur.

Examples:

- Immunization (e.g., polio, rubella),
- prenatal care,
- genetic counseling,
- road safety campaigns.

Secondary Prevention:

Focuses on early detection and intervention to minimize severity.

Examples:

- Neonatal screening, early therapy for developmental delays.

Tertiary Prevention:

Reduces the impact of an already existing disability.

Examples:

- Rehabilitation services, provision of assistive devices (e.g., hearing aids, prosthetics),
- Inclusive education

Tests used in early identification of disabilities or diseases that may lead to disabilities

Prenatal Screening Tests Table

Test	Condition Detected	Elevated Levels	Decreased Levels
Maternal Alpha-Fetoprotein (AFP)	Neural tube defects, Down syndrome, Trisomy 18	Neural tube defects, abdominal wall defects	Down syndrome, Trisomy 18, fetal demise
hCG (Human Chorionic Gonadotropin)	Down syndrome, Trisomy 18	Down syndrome	Trisomy 18, fetal growth restriction
Estriol (μ E3)	Chromosomal abnormalities (Down syndrome, Trisomy 18)	-	Down syndrome, Trisomy 18
Inhibin-A	Down syndrome	Down syndrome	-
Amniocentesis	Chromosomal and genetic disorders, metabolic errors	Results based on genetic analysis	Results based on genetic analysis
Ultrasound	Structural defects (neural tube defects, cleft lip)	N/A	N/A



Tests used in early identification of disabilities or diseases that may lead to disabilities

Modern Neonatal Screening Tests

Test	Conditions Detected	Timing	Details
Newborn Blood Spot Test	<ul style="list-style-type: none">- Phenylketonuria (PKU)- Congenital Hypothyroidism- Cystic Fibrosis- Sickle Cell Disease- Galactosemia- Congenital Adrenal Hyperplasia	24–72 hours after birth	Heel prick to analyze blood for metabolic, endocrine, and hemoglobin disorders
Hearing Screening	Hearing Loss or Deafness	Within the first few days	Uses Otoacoustic Emissions (OAE) or Auditory Brainstem Response (ABR) to measure hearing response
Pulse Oximetry Screening	Critical Congenital Heart Disease (CCHD)	24–48 hours after birth	Measures oxygen saturation levels using a small probe on the hand or foot

Required interventions

Equalization of opportunities:

- It is the process through which the general system of society are made accessible to all such as:
 - The physical and cultural environment,
 - Housing and transportation,
 - Social aid health services,
 - Educational and work opportunities,
 - Cultural and social life, including sports and recreational facilities, are made accessible to all.



Overview of PWD in Jordan:

Approximately **11.1%** of individuals aged 5 and above in Jordan have reported disabilities or difficulties, equating to roughly **651,396** people. Disability prevalence is slightly **higher among males (11.5%)** compared to females (**10.6%**).



The Hashemite Kingdom of Jordan
Law No. (20) for the Year 2017
Law on the Rights of Persons with Disabilities Act

Article (1)

This law shall be called and cited as “the Law on the Rights of Persons with Disabilities No. 20 for the Year 2017”, and will go into effect 90 days after being published in the Official Gazette.

https://www.un.org/development/desa/disabilities/wp-content/uploads/sites/15/2019/11/Jordan_Law-No.-20-for-the-year-2017-on-the-Law-on-the-Rights-of-Persons-with-Disabilities.pdf



المجلس الأعلى لحقوق
الأشخاص ذوي الإعاقة
Higher Council for the Rights of
Persons with Disabilities (HCD)

<https://hcd.gov.jo/Default/En>

Legal Framework:

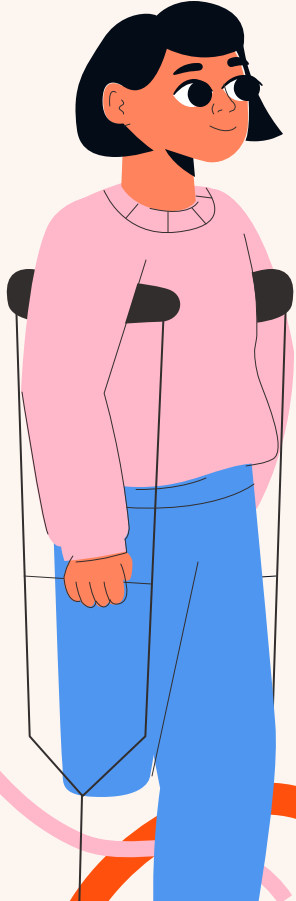
- Law No. 20 (2017):

Aligns Jordan's disability policies with the UNCRPD.

- Establishment of the Higher Council for the Rights of Persons with Disabilities (HCD)

to oversee implementation.

Key Challenges Faced by PWD in Jordan



Education Challenges for PWD:

Only 5.9% of Persons with Disabilities (PWDs) complete education beyond the secondary level.

Inclusive education programs remain scarce due to insufficient infrastructure, lack of assistive technologies, and adapted curricula.

Only 2% of schools meet accessibility standards.

Health Challenges for PWD:

Many PWDs are not covered or face high out-of-pocket costs for medical needs.

Around 51% of PWDs report difficulty accessing healthcare services (UNICEF, 2023).

Employment and Social Integration:

High unemployment rates among PWDs due to discrimination and lack of training.

PWD unemployment in Jordan exceeds 85% (HI, 2023).

Women with disabilities are 40% less likely to be employed than men (WADA Institute, 2023). "double discrimination"



Positive Developments in Jordan

Inclusive Policies:

Implementation of construction guideline to increase accessibility for public buildings.

Government programs include PWD in arts, culture, and sports.

Health Initiatives:

- **Introduction of neonatal screening programs for conditions like PKU and congenital hypothyroidism.**



Thanks!



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PUSH YOURSELF,
BECAUSE NOBODY ELSE
IS GOING TO DO
IT FOR YOU.