

PRIDE PROVIDER : MODULE 1

DEFINING DISABILITY, DISABILITY RIGHTS, STIGMA, AND DISCLOSURE IN THE U.S.



MODULE OVERVIEW

- **Definitions of disability**
- **Facts about people with disabilities**
- **Facts about employment and refugees with disabilities**
- **Types of disabilities**
- **Disability models**
- **Legal frameworks and relevant legislation**
- **Discussing disability, employment, and disclosure with clients**
- **Disability rights organization**
 - **Featured PRIDE partner: Equip for Equality**
- **Case example**

DEFINITION OF DISABILITY

The Merriam-Webster Dictionary defines a disability as “a physical, mental, cognitive, or developmental condition that impairs, interferes with, or limits a person's ability to engage in certain tasks or actions or participate in typical daily activities and interactions.”



WHAT ARE SOME WAYS THAT “DISABILITY” IS DEFINED?

One way to understand disability is to become familiar with established definitions of disability and types of disabilities.

Disabilities are physical/mobility, intellectual, developmental, sensory, mental health, and/or chronic health conditions or diagnoses that impact life activities.

The definition of disability can differ by culture, and the word “disability” may not directly translate into languages commonly spoken by refugees. This can lead to confusion and misunderstandings related to the label of “disability” used in the U.S., which can be stigmatizing.

AN IMPORTANT NOTE

- ✓ It is important to acknowledge that a refugee may not consider his/her condition or diagnosis to be a disability.
- ✓ However, a refugee's condition or diagnosis may be considered a disability in the U.S., which may allow him/her to access additional local employment resources and services specifically for people with disabilities.
- ✓ Access to these supports can lead to increased engagement and participation in daily activities and in the community.



FACTS ABOUT PEOPLE WITH DISABILITIES

There are many facts about refugees and people with disabilities cited by credible sources. The information below comes from the World Health Organization, the Women's Refugee Commission², and the U.S. Census.



In the world, more than 1 billion people, or about 15% of the population, live with some form of disability.²



Among people displaced due to conflict throughout the world, 7.7 million of 51 million have disabilities.



In the U.S., 56.7 million people, or about 19% of the population, had a disability in 2010.⁴

FACTS ABOUT PEOPLE WITH DISABILITIES (CONT'D)



Disability disproportionately affects vulnerable populations, who may have also experienced discrimination, exploitation, and violence, such as women, older people, and people who are economically disadvantaged.



There is evidence that rates of violence may be 4 to 10 times greater among refugees with disabilities compared to refugees without disabilities.



People with disabilities often do not receive needed health care, assistive technology, or social services due to a variety of cultural, attitudinal, and institutional barriers.



People with disabilities are more susceptible to poverty due to lack of employment opportunities combined with disability-related expenses. (e.g., rehabilitation and medical costs).

FACTS ABOUT EMPLOYMENT AND REFUGEES WITH DISABILITIES



People with disabilities, including refugees, are often denied equitable access to education, vocational training, and employment.



Compared to refugees without disabilities, refugees with disabilities are more likely to be unemployed or underemployed.³



Refugees with disabilities' potential contribution to the workforce is often overlooked.



With the right supports, people with disabilities can more fully participate in many aspects of life (e.g., employment, education, community events, and spiritual/religious activities).

TYPES OF DISABILITIES

- ✓ **Many service support systems use different definitions or descriptions of disability that link to their eligibility criteria.**
- ✓ **It is important to be aware of the different definitions and the role they play in refugees with disabilities' ability to access resources and supports across different service agencies.**
- ✓ **The next few slides describe different types of disabilities as defined by the U.S. Census Bureau and other credible sources; however, there is no standard definition of disability used among government agencies that support people with disabilities.**

PHYSICAL DISABILITY



- A physical disability refers to a condition that substantially limits one or more physical activities such as walking, climbing stairs, reaching, lifting, or carrying.
- This type of disability can impact mobility inside and outside of the home and participation in the community.
- This type of disability can also affect performance of self-care activities, such as dressing, bathing, or eating or drinking.
- People with physical disabilities may use assistive devices such as reachers, modified utensils, canes, walkers, or wheelchairs.

PHYSICAL DISABILITY



- Physical disabilities can be apparent at birth or can be acquired later in life.
- Some common examples of conditions that can cause physical disabilities are include muscular dystrophy, cerebral palsy, polio, amputations, and spinal cord injuries.
- Chronic conditions, such as stroke, arthritis, obesity, diabetes, heart or kidney disease, and cancer, can also affect mobility and self-care.

COGNITIVE DISABILITY



- Physical disabilities can be apparent at birth or can be acquired later in life.
- Some common examples of conditions that can cause physical disabilities are include muscular dystrophy, cerebral palsy, polio, amputations, and spinal cord injuries.
- Chronic conditions, such as stroke, arthritis, obesity, diabetes, heart or kidney disease, and cancer, can also affect mobility and self-care.

HEARING AND VISUAL DISABILITY



- Physical disabilities can be apparent at birth or can be acquired later in life.
- Some common examples of conditions that can cause physical disabilities are include muscular dystrophy, cerebral palsy, polio, amputations, and spinal cord injuries.
- Chronic conditions, such as stroke, arthritis, obesity, diabetes, heart or kidney disease, and cancer, can also affect mobility and self-care.

HEARING AND VISUAL DISABILITY (CONT'D)



- A hearing or visual disability can be apparent at birth or acquired later in life.
- A person with a hearing or visual disability may require assistive devices or services such as hearing aids, amplifiers, sign language interpretation, reading magnifiers, modified or specialized reading materials, and/or canes.
- People with visual disabilities and those with combined hearing and visual disabilities can experience difficulty with mobility, community participation, and self-care.
- Acquired injuries and chronic health conditions, such as diabetes and cancer, can affect vision and hearing.

ANOTHER WAY TO UNDERSTAND DISABILITY: DISABILITY MODELS

- **A second way to understand disability is through the framework of disability models.**
- **Historically, in the U.S. and many parts of the world, disability has been viewed through the lens of the “Medical Model.”**
- **The Medical Model is associated with the medical community and a deficits-focused view of disability.**
- **In the 1980s, the “Social Model” emerged in reaction to the dominant Medical Model.⁶**
- **The Social Model is associated with the disability rights community and an environmental barrier- and empowerment-focused view of disability.**

DEFINING THE MEDICAL MODEL VS. SOCIAL MODEL

Medical Model	Social Model
Disability is something that must be fixed.	Disability is a natural part of life that will impact most people. In order to support people with disabilities, rather than treating the disability, the best approach is to address social and environmental barriers.
Doctors and other professionals know what is best for people with disabilities.	People with disabilities are their own best advocates and should be involved in all decisions that govern their lives.
People with disabilities have special needs.	People with disabilities have civil rights.
Institutional/Segregated Services for people with disabilities	Independent Living/Community-Based Services

ANOTHER WAY TO UNDERSTAND DISABILITY: LEGAL FRAMEWORKS

- **A third way to define disability is by drawing upon commonly-recognized legal frameworks.**
- **One such framework is offered by the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).**
- **The UNCRPD is an international human rights treaty designed to protect the rights and dignity of persons with disabilities.**
- **The UNCRPD defines disability as:**
 - **“An evolving concept...that 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.”**

U.S. LEGAL FRAMEWORK



- Signed into law in 1990 and amended in 2008, the Americans with Disabilities Act (ADA) offers another legal definition of disability.
- Under the ADA, a person is considered to have a disability if he/she:
 - “has a physical or mental impairment that substantially limits one or more major life activities, has a history or record of such an impairment, or is perceived by others as having such an impairment.”⁹
- The ADA covers individuals with visible disabilities (e.g., a spinal cord injury) and hidden or invisible disabilities (e.g., Post-traumatic Stress Disorder, or PTSD).

THE AMERICANS WITH DISABILITIES ACT (ADA)

The ADA includes 5 sections, or titles⁹:

- **Title I (Employment) prohibits employers with 15 or more employees from discriminating against people with disabilities in hiring, promotion, and termination procedures, job training, and other terms, conditions, and privileges of employment.**
 - **Note: The Illinois Human Rights Act covers employers with fewer than 15 employees.**

THE AMERICANS WITH DISABILITIES ACT (ADA) – CONT'D

- **Title II (Public Entities)** prohibits discrimination against people with disabilities in programs and services offered by public entities such as school districts, public housing, and public transportation. Public entities are also expected to create accessible spaces and programs that are inclusive of people with disabilities.

THE AMERICANS WITH DISABILITIES ACT (ADA) – CONT'D

- **Title III (Public Accommodations) prohibits discrimination against people with disabilities in public accommodations and commercial facilities such as hotels, restaurants, museums, etc.**
 - **Note: Under Title III, all new constructions are expected to be fully compliant with the Americans With Disabilities Act Accessibility Guidelines. Existing facilities are expected to remove architectural barriers as long as doing so is not cost prohibitive for the entity.**

THE AMERICANS WITH DISABILITIES ACT (ADA) – CONT'D

- **Title IV (Telecommunications) requires telecommunications companies in the U.S. to offer equivalent services for people with disabilities, particularly those who are Deaf or hard of hearing and those with speech impairments.**
- **Title V (Miscellaneous Provisions) includes technical provisions and prohibits retaliation against or coercion of people with disabilities who try to exercise their rights.**

OTHER DISABILITY-RELATED LEGISLATION IN THE U.S.

- **The Fair Housing Act (1968)**
 - Prohibits housing discrimination on grounds of disability.
 - Requires landlords to make reasonable exceptions in their policies and operations to allow equal housing opportunities for people with disabilities. For example, a landlord with a "no pets" policy may be required to grant an exception for a guide dog or service animal.
 - Requires landlords to allow tenants with disabilities to make reasonable, access-related modifications to their private living space, as well as to common use spaces. (The landlord is not required to pay for the changes.)¹⁰

OTHER DISABILITY-RELATED LEGISLATION IN THE U.S.

- **Rehabilitation Act (1973)**
 - **Section 501 requires affirmative action and nondiscrimination in employment by Federal agencies of the executive branch.**
 - **Section 503 requires affirmative action and prohibits employment discrimination by Federal government contractors and subcontractors.**
 - **Section 504 prohibits discrimination against people with disabilities in any program or activity that either receives federal financial assistance or is conducted by any Executive agency or the United States Postal Service.¹⁰**

OTHER DISABILITY-RELATED LEGISLATION IN THE U.S.

- **Individuals with Disabilities Education Act (IDEA) - 1990**
 - **Requires that public schools make education available to children with disabilities in the least restrictive environment possible.**
 - **Ensures that eligible students with disabilities are provided with free and appropriate public education that is tailored to their needs.**
 - **Requires public school systems to develop an appropriate Individualized Education Program (IEP) for each child.¹⁰**

OTHER DISABILITY-RELATED LEGISLATION IN THE U.S.

- **Olmstead Decision (1999)**
 - **Requires states to eliminate unnecessary segregation of people with disabilities in institutions such as nursing homes and mental hospitals, as well as in segregated employment settings such as sheltered workshops**
 - **Ensures that people with disabilities receive services and participate in the most integrated settings appropriate to their needs¹¹**



**DISCUSSING DISABILITY AND
EMPLOYMENT WITH CLIENTS**



RESPECTFUL DISABILITY LANGUAGE

- Many disability activists and advocates in the U.S. subscribe to the Social Model of disability. Therefore, “disabled people” is their preferred terminology to signify that people are “disabled” by their environment.
- Using person-first language, such as “people with disabilities” is also acceptable and is more commonly used in other countries.
- In general, it is safest to ask the people whom you are with which term they prefer if they have a disability.
- [More language tips from Mobility International-USA](#)

DISABILITY STIGMA

- **In many cultures and countries, including the U.S., having a disability is associated with shame and stigma.**
- **As a result, many people are reluctant to disclose their disability or to identify as a person with a disability.**
- **This can pose a challenge for service providers.**

DISABILITY STIGMA

Service providers can take the following steps when broaching this sensitive and potentially stigmatizing topic:

- **Ensure that an interpreter is available if the client is not proficient in spoken English.**
- **Try to learn about the client's past history and background.**
- **Explore how the client's impairment or condition is viewed in his/her native culture.**
- **Describe the legal protection and community supports available to people with disabilities in the U.S.**
- **Emphasize the importance of self-identifying as a person with a disability to receive disability-related supports and legal protection.**
- **Try to connect the client with role models and peers with disabilities.**

KEY POINTS WHEN DISCUSSING EMPLOYMENT OPTIONS WITH REFUGEES WITH DISABILITIES

- **Refugees with disabilities have the right to work in the U.S.**
- **According to Article 23 of the Universal Declaration of Human Rights¹²:**
 - **Everyone has the right to decent work, choice of employment, equitable work conditions, and fair pay, ensuring human dignity for themselves and their families.**
- **Refugees with disabilities have much to contribute to the U.S. workforce.**
- **Refugees with disabilities have transferrable skills and unique experiences that they can bring to U.S. workplaces.**

KEY POINTS WHEN DISCUSSING EMPLOYMENT OPTIONS WITH REFUGEES WITH DISABILITIES (CONT'D)

- **Refugees with disabilities can find and obtain employment in the U.S.**
- **Refugees with disabilities have a very important role to play in the U.S. workforce. Supports and services are available to help refugees with disabilities find and obtain employment.**
- **It is possible for refugees with disabilities to work and keep or adjust their SSI/SSDI benefits. This is a common point of concern for refugees with disabilities. More information on this topic is available in Module 2 of the provider training.**

EMPLOYMENT AND DISCLOSURE

- It is important for job seekers with disabilities to confront the possibility of disclosing their disability to their potential employer so that they can have the right kinds of supports in place to be successful.
- If a refugee client with a disability prefers not to disclose his/her disability because of concerns about stigma or unfair treatment, he/she should be made aware that an employer cannot discriminate on grounds of disability.
- A refugee client with a disability can also choose to disclose general information about his/her disability without sharing specific details.¹³

EMPLOYMENT AND DISCLOSURE (CONT'D)

- **Before making a decision, the individual should consider how disability affects his/her ability to perform job duties and types of accommodations that would be helpful.**
- **Disclosing a disability may help the individual gain accommodations that will support performance of job duties. For example, an employee who is easily distracted may prefer to work in a quiet workspace versus in a large room with lots of cubicles and noise.**
- **Nevertheless, the decision to disclose a disability is entirely up to the person with a disability.¹³**

HOW CAN PROVIDERS HELP CLIENTS WITH DISABILITIES MAKE AN INFORMED DECISION ABOUT DISCLOSURE?

- **Make sure that an interpreter is available if the client is not proficient in English so that he/she understands all the pros and cons of disclosing his/her disability to his/her employer or potential employer.**
- **Make the client aware of his/her right to privacy and confidentiality regarding his/her disability.**
- **Prepare the client for what may happen if he/she does or does not choose to disclose a disability.**
- **Ask questions to learn about the client's disability and need for workplace accommodations to determine whether disclosing the disability is the best option.**

DISABILITY RIGHTS ORGANIZATIONS

- **Several organizations exist to monitor implementation of disability-related legislation in the U.S.**
- **These organizations, known as Protection and Advocacy (P&A) agencies, strive to protect the rights of people with disabilities as enshrined in U.S. law.¹⁴**
- **P&A agencies have the authority to provide legal representation and other advocacy services, under all federal and state laws, to all people with disabilities.¹⁴**
- **Equip for Equality, a PRIDE partner, is the designated Protection and Advocacy Agency for people with disabilities in Illinois.**

WHAT ARE EQUIP FOR EQUALITY'S CORE SERVICES?

- **Promoting self-advocacy and serves as a legal advocate for people with disabilities handling individual cases and systems-change litigation to achieve broad-based societal reforms**
- **Independently monitoring public and private institutions and programs serving people with disabilities**
- **Serving as a watchdog over the government, business, and not-for-profit sectors**
- **Advocating through public policy and legislative activities to give people greater choices in their lives and ensure their independence and inclusion in all aspects of community living**
- **Empowering people and their families through disability rights trainings so they can advocate for themselves or others¹⁵**

HOW CAN EQUIP FOR EQUALITY SUPPORT JOB-SEEKING REFUGEES WITH DISABILITIES?

- **Equip for Equality operates an employment helpline for people with disabilities.**
- **This is a free statewide service providing people with disabilities with legal rights information and self-advocacy assistance to help navigate employment issues that arise.**
- **Helpline staff can:**
 - **Discuss legal rights under the ADA**
 - **Answer employment rights questions**
 - **Assist with reasonable accommodation requests**
 - **Help understand options**
 - **Share fact sheets, sample letters, and forms¹⁵**
- **Contact the Helpline: 1-844-RIGHTS-9 or 1-844-744-4879 or employment@equipforequality.org**

HOW CAN EQUIP FOR EQUALITY SUPPORT JOB-SEEKING REFUGEES WITH DISABILITIES? (CONT'D)

- **Sometimes people with disabilities are unable to resolve employment discrimination issues on their own; in these cases, Equip for Equality attorneys can provide legal representation.**
- **Legal representation can include:**
 - **Negotiations with employers to resolve workplace disputes, such as reasonable accommodations**
 - **Representation at administrative hearings and mediation, including at the Equal Employment Opportunity Commission or the Illinois Department of Human Rights**
 - **Representation in federal court¹⁵**

HOW CAN EQUIP FOR EQUALITY SUPPORT JOB-SEEKING REFUGEES WITH DISABILITIES? (CONT'D)

- Equip for Equality provides a training for people with disabilities on their employment rights called: “Put Your Rights to Work: The Americans with Disabilities Act and Employment.”
- This training focuses on:
 - ① Advocating for one’s rights at job interviews and on the job
 - ② Practicing handling employers’ questions
 - ③ Asking for reasonable accommodations¹⁵
- [Link for more information and training requests](#)

EQUIP FOR EQUALITY'S EMPLOYMENT FIRST POLICY WORK

- In 2013, Illinois passed the Employment First Act, which states that competitive integrated employment should be the first option for people with disabilities.
- Equip for Equality developed the [Employment First Blueprint](#), which provides concrete steps to assist Illinois with implementing the Employment First Act.
- Equip for Equality sits on the Governor's Task Force for the Employment and Economic Opportunity for People with Disabilities, whose duties include implementation of the Employment First Act.¹⁵

WHO IS ELIGIBLE FOR EQUIP FOR EQUALITY'S SERVICES?

- **People of all ages with all types of disabilities are eligible for Equip for Equality's services.**
- **This is a statewide organization with offices in four locations: Chicago, Springfield, Carbondale, and Moline.**
- **There is no citizenship or income requirement to be eligible for services.**
- **The only requirement is that the client be a person with a disability whose legal concern or problem arose in Illinois.¹⁵**

CONTACT EQUIP FOR EQUALITY - CHICAGO

Chicago (Main Office and Northeast Region)

Address: 20 North Michigan Avenue, Suite 300
Chicago, IL 60602

Phone: 312-341-0022 or 800-537-2632 (Voice)
800-610-2779 (TTY); 312-541-7544 (Fax)

Email: contactus@equipforequality.org

Website: www.equipforequality.org

Facebook: www.facebook.com/equipforequality/

Twitter: [@equip4equality](https://twitter.com/equip4equality)

You Tube: www.youtube.com/user/EquipforEquality

CONTACT EQUIP FOR EQUALITY – REGIONAL OFFICES

Northwest Region:

1515 Fifth Ave., Suite 420

Moline, IL 61265

309-786-6868 or 800-758-6869; 800-610-2779 (TTY)

Central Region:

1 West Old State Capitol Plaza, Suite 816

Springfield, IL 62701

217-544-0464 or 800-758-0464; 800-610-2779 (TTY)

Southern Region:

300 East Main St., Suite 18

Carbondale, IL 62901

618-457-7930 or 800-758-0559; 800-610-2779 (TTY)

CASE EXAMPLE

Frederick is a refugee from the Democratic Republic of Congo who arrived in Chicago approximately 15 months ago. He speaks fairly fluent English and is industrious.

Shortly after arriving, Frederick found a job as a bellhop at a downtown luxury hotel with the help of a resettlement agency. Frederick has seizure disorder, which he did not disclose to his employer when he applied, interviewed, or was hired for the job.

Six months ago, while at work, Frederick had a grand mal seizure. He was taken to the ER, where the attending physician recommended that he consult with his neurologist for a change of prescription. While Frederick was awaiting his neurology consult, his employer terminated his job without citing any reasons for dismissal.

CASE EXAMPLE (CONT'D)

Under his neurologist's supervision, Frederick is trialing a new seizure medication, which his doctor believes will better control his grand mal seizures. He has had no recurrence of seizures since he began this medication.

Frederick would like to return to work and believes he was dismissed because he had a seizure. Frederick approaches Lucy, the employment manager at his resettlement agency. Lucy decides to approach Equip for Equality to investigate Frederick's case and legally represent him if needed.

After filing a complaint with the Equal Employment Opportunity Commission, or EEOC, Frederick was given a "right to sue" letter, and Equip for Equality agreed to review his case.

CASE EXAMPLE (CONT'D)

Frederick's employer argued that his termination was legal under the ADA as he posed a significant risk of substantial harm to himself if he continued his job.

His legal representative used his medical records to argue that this risk was significantly reduced with new medication. A settlement was negotiated that allowed Frederick to return to a similar job at a different hotel. He also received back pay, emotional distress damages, and attorney's fees.

SOURCES

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<https://www.census.gov/people/disability/>

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5. Centers for Disease Control and Prevention

<https://www.cdc.gov/ncbddd/disabilityandhealth/data.html>

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7. Arnold, G. (2017). Disability Awareness Presentation. University of Illinois at Chicago, Chicago, IL, February 28, 2017.

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<http://www.un.org/en/universal-declaration-human-rights/>

SOURCES (CONT'D)

9. U.S. Department of Labor

<https://www.dol.gov/general/topic/disability/ada>

10. Americans with Disabilities Act

<https://www.ada.gov/cguide.htm#anchor63409>

11. Americans with Disabilities Act – Olmstead Act

<https://www.ada.gov/olmstead/>

12. United Nations - Universal Declaration of Human Rights

<http://www.un.org/en/universal-declaration-human-rights/>

SOURCES (CONT'D)

**13. U.S. Department of Labor – Office of Disability
Employment Policy**

<https://www.dol.gov/odep/pubs/fact/ydw.htm>

14. National Disability Rights Network

<http://www.ndrn.org/about/paacap-network.html>

15. Equip for Equality

<http://www.equipforequality.org/>