**PRIDE Provider Module #1:**

**Defining Disability, Disability Rights, Stigma, and Disclosure**

Transcript

Hello and welcome to PRIDE Provider Module 1: Defining Disability, Disability Rights, Stigma, and Disclosure in the U.S. This module features PRIDE partner agency Equip for Equality, a disability rights and advocacy organization.

Module overview. This module will include 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 organizations, including featured PRIDE partner Equip for Equality, and it will conclude with a case example.

Definition of disability. There are many definitions of disability. Here is a basic definition from Merriam-Webster: A disability is “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.” Notice that the emphasis is on the condition’s impact on engaging in tasks and participating in daily activities.

What are some other ways that “disability” is defined? We can better understand disability by becoming 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. One important point that PRIDE has learned from experience and from its partner agencies is that the definition of disability can differ by culture. Refugees may not have words in their languages that translate exactly to “disability.” This can lead to confusion and misunderstandings. Just as in the U.S., there may be cultural stigmas surrounding the label of having a “disability.”

It is important to acknowledge that a refugee may not consider a condition or diagnosis that he or she has to be a disability. However, a refugee’s condition or diagnosis may be considered a disability in the U.S., which may allow him or 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. Now that we’ve gone over some general definitions and important points to think about when working with refugee clients who may have disabilities, we’ll share some statistics and facts about people with disabilities. The information on this slide comes from the World Health Organization, the Women’s Refugee Commission, and the U.S. Census. Around the world disability affects 1 billion people, or 15% of the world’s population. This includes 7.7 million of the world’s 51 million displaced persons. In the U.S. there were about 57 million people with disabilities in 2010. This number amounts to 19% of the U.S. population. These statistics make it clear just how prevalent disabilities are in the U.S. and throughout the world.

Facts about people with disabilities, continued. Disability particularly impacts vulnerable populations, who may have also experienced discrimination, exploitation, and violence, such as women, older people, and people who are economically disadvantaged. Among refugees with disabilities, another vulnerable population, rates of violence may be 4 to 10 times greater than for refugees without disabilities. Due to the multiple barriers that people with disabilities face, including cultural, attitudinal, and institutional barriers, they often do not receive needed health care, assistive technology, or social services. Furthermore, people with disabilities are more susceptible to poverty due to lack of employment opportunities combined with disability-related expenses such as rehabilitation and medical costs.

Facts about employment and refugees with disabilities. Refugees with disabilities face a variety of barriers related to employment, and, as a result, they are more likely to be unemployed or underemployed. A major barrier is lack of access to education and/or vocational training, which can limit employment opportunities. Limited employment opportunities, in turn, can lead to poverty, which may be made even worse by medical and other health-related expenses. Due to their disabilities, their potential contribution to the workforce is often overlooked. With the right supports, however, refugees with disabilities DO have many things to contribute to the U.S. workforce. Furthermore, having viable and desirable employment can have a major impact on their lives, enabling them to more fully participate in many aspects of many aspects of life such as employment, education, community events, and spiritual and religious activities.

The next section of the module provides an overview of different types of disabilities, which are defined differently by different cultures, agencies, and systems. In the U.S., the way that disabilities are defined and categorized can have a major impact on the lives of people with disabilities as these definitions and categories link to eligibility criteria for resources and services. There are no standard criteria used across U.S. service systems. The disability types included in this module come from the U.S. Census Bureau and other credible sources.

Physical disability. This type of disability may be more visible or apparent than some other types of disabilities. Physical disabilities refer to conditions that substantially limit one or more physical activities such as walking, climbing stairs, reaching, lifting, or carrying, which can impact mobility inside and outside of the home and community participation. It can also affect one’s ability to perform self-care activities such as dressing, bathing, eating, or drinking. People with physical disabilities may use assistive devices such as reachers, modified utensils, canes, walkers, or wheelchairs.

Physical disability, continued. A person can have a physical disability from birth or can acquire one at any point later in life. Specific conditions that can result in physical disabilities are 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 impact mobility and self-care.

The next disability type is cognitive disabilities. Something that we want to highlight is that cognitive disabilities and related mental health conditions are a common area of confusion for individuals, family members, and service providers. There are many causes of this type of disability, which refers to difficulty learning, remembering, concentrating, or making decisions because of a physical, mental, or emotional condition. These conditions include intellectual and developmental conditions, such as Down Syndrome; chronic progressive conditions, such as dementia; and mental health conditions, such as depression and Post-Traumatic Stress Disorder, or PTSD. People with cognitive disabilities can also experience difficulty with mobility inside and outside of the home, community participation, and self-care.

Hearing and visual disabilities. A hearing disability can mean total deafness or serious difficulty hearing. People with this type of disability may or may not know a sign language, of which there are many. For example, in the U.S., American Sign Language, or ASL, is commonly used, but refugees who are Deaf or hard of hearing may use a different sign language to communicate. A visual disability can mean blindness or serious difficulty seeing. An important point is that the difficulty seeing must be present even with corrective lenses. People with visual disabilities may or may not know how to read Braille or raised letters.

Hearing and visual disabilities can occur from birth or later in life. People with these types of disabilities may need assistive devices or services such as hearing aids, amplifiers, sign language interpretation, reading magnifiers, modified or specialized reading materials, and/or white 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.

In addition to being familiar with definitions and types of disabilities, we can also understand disability through the use of models. Two models that are often discussed are the Medical Model and the Social Model of Disability. The Medical Model is associated with the medical community and a deficits-focused view of disability. The Social Model emerged as a reaction to the dominant Medical Model in the 1980s. The Social Model is associated with the disability rights community and an environmental barrier- and empowerment-focused view of disability.

Defining the Medical Model versus the Social Model. In the Medical Model, disability is something that must be fixed, while in the Social Model, 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 according to the Social Model is to address social and environmental barriers. In the Medical Model, doctors and other professionals know what is best for people with disabilities. On the other hand, in the Social Model, people with disabilities are their own best advocates and should be involved in all decisions that impact their lives. In the Medical Model, people with disabilities have special needs, whereas in the Social Model people with disabilities have civil rights. Finally, the Medical Model is associated with institutional or segregated services for people with disabilities, while the Social Model advocates for independent living and community-based services for people with disabilities.

Disability can also be understood through commonly-recognized legal frameworks such as that of the United Nations Convention on the Rights of Persons with Disabilities, or UNCRPD. The UNCRPD is an international human rights treaty designed to protect the rights and dignity of persons with disabilities. According to the UNCRPD, disability is “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. While the UNCRPD offers a more global view of disability, the Americans with Disabilities Act, or ADA, provides a legal definition of disability in the U.S. The ADA was signed into law in 1990 and amended in 2008. According to the ADA, a person is considered to have a disability if he or 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.” This disability may be apparent, or visible—for example, a physical disability such as a spinal cord injury that results in the use of a wheelchair, or it may not be apparent, or invisible—for example, a cognitive or independent living disability such as a mental health condition like PTSD.

The Americans with Disabilities Act, or ADA. The ADA has 5 sections, or titles.9 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.

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.

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

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.

Finally, 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. Another prominent disability-related law is the Fair Housing Act of 1968, which prohibits housing discrimination on grounds of disability. This Act 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. The Fair Housing Act also 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, however.

Another major disability-related U.S. law is the Rehabilitation Act of 1973, which requires affirmative action and nondiscrimination in employment by Federal agencies of the executive branch under Section 501. This Act also requires affirmative action and prohibits employment discrimination by Federal government contractors and subcontractors under Section 503. In addition, the Rehabilitation Act 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 under Section 504.

A prominent disability-related U.S. law that applies to education is the Individuals with Disabilities Education Act, or IDEA, of 1990. The IDEA requires that public schools make education available to children with disabilities in the least restrictive environment possible. It also ensures that eligible students with disabilities are provided with free and appropriate public education that is tailored to their needs and requires public school systems to develop an appropriate Individualized Education Program, or IEP, for each child.

Finally, the landmark Olmstead Decision of 1999 declared that people with disabilities should be integrated into the community, specifically requiring that states eliminate unnecessary segregation of people with disabilities in institutions such as nursing homes and mental hospitals. It has also been interpreted to apply to segregated employment settings such as sheltered workshops. Olmstead also determined that people with disabilities should receive support services so that they may participate in the most integrated settings appropriate to their needs.

The next section of the module will provide information on discussing disability and employment with clients.

Respectful disability language. When discussing disability and employment with clients, it’s important to be aware of some specific points related to language. For example, 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. “Person-first” language, in which the word “person” precedes reference to the condition or disability, is also recommended. This is more commonly used in other countries. However, it’s safest to ask the people you are interacting with which terms they prefer if they have disabilities. Mobility International-USA has more language tips for working with people with disabilities—please see the link provided on this slide.

Disability stigma. Focusing on language and being aware of the sensitive nature of discussions about disability are important because in many cultures and countries, including the U.S., having a disability may be associated with shame and stigma. As a result of this stigma, many people are reluctant to disclose their disability or identify as a person with a disability. Therefore, addressing disability with clients can be a challenge for service providers.

Disability stigma, continued. There are some strategies that service providers can use to improve communication with clients with respect to the sensitive and potentially stigmatizing topic of disability. As a service provider, you can take the following steps when broaching this 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 avail of disability-related supports and legal protection; finally, 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. For example, they have transferrable skills and unique experiences that they can bring to U.S. workplaces.

Other key points when discussing employment with refugees with disabilities include: Refugees with disabilities can find and obtain employment in the U.S. They have a very important role to play in the U.S. workforce. Supports and services are available to help them 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. Here are some important points to be aware of and to discuss with refugee clients with disabilities related to disclosure of their disability to an employer or potential employer. 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 or her disability because of concerns about stigma or unfair treatment, he or 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 or her disability without sharing specific details.13

Employment and disclosure, continued. Before making a decision, the individual should consider how the 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 would support performance of job duties. For example, an employee who is easily distracted may prefer to work in a quiet work space 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

So, how can providers support clients to make informed decisions

about disclosure of their disabilities? 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 medical condition. Prepare the client for what may happen if the client does or does not choose to disclose his/her disability. Learn and ask questions about the client’s disability and his/her need for workplace accommodations to determine whether disclosing his/her disability is the best option.

There are also disability rights organizations that can provide information to clients about laws in the U.S. and advocate for their rights. For example, Protection and Advocacy, or P and A, agencies, work to protect rights of people with disabilities as codified in U.S. law. These agencies have the authority to provide legal representation and other advocacy services, under all federal and state laws, to all people with disabilities. Equip for Equality, a PRIDE partner, is featured in this module as the designated Protection and Advocacy Agency for people with disabilities in Illinois.

Equip for Equality provides numerous services to achieve its advocacy aims. For example, it promotes 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 monitors public and private institutions and programs serving people with disabilities; serves as a watchdog over the government, business, and not-for-profit sectors; advocates 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; and empowers people and their families through disability rights trainings so they can advocate for themselves or others.15

Equip for Equality can support job-seeking refugees with its employment helpline, which may be accessed by phone at the number provided at the bottom of the slide. This is a free statewide service that provides legal rights information and self-advocacy assistance to people with disabilities when employment issues arise. The helpline staff can discuss legal rights under the ADA; answer employment rights questions; assist with reasonable workplace accommodation requests; help clients understand their options; and share fact sheets, sample letters and forms. The helpline can be accessed by phone at 1-844-RIGHTS-9 or online at employment@equipforequality.org

Equip for Equality can also support job-seeking refugees with disabilities by providing them with direct legal services including formal 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; and even representation in federal court.

Equip for Equality also offers a training, which refugees with disabilities can take advantage of, called “Put Your Rights to Work: The Americans with Disabilities Act and Employment.” The training focuses on advocating for one’s rights on the job and at job interviews, practicing handling employers’ questions, and asking for reasonable workplace accommodations. You can get more information or request a training on Equip for Equality’s website.

Equip for Equality also does policy work. The agency developed the Employment First Blueprint, which provides concrete steps to assist Illinois with implementing the Employment First Act, a 2013 state law that states that competitive integrated employment should be the first option for people with disabilities. Equip for Equality is part of the Governor’s Task Force for the Employment and Economic Opportunity for People with Disabilities, whose duties include implementation of the Employment First Act. More information can be found on Equip for Equality's website.

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, which may be accessed at 4 statewide locations in Chicago, Springfield, Carbondale, and Moline. There is no citizenship or income requirement, but the legal concern must have arisen in Illinois to be addressed through Equip for Equality.

This slide contains the contact information for Equip for Equality’s main office in Chicago.

This slide contains the contact information for Equip for Equality’s three additional regional offices.

Here is a fictional case example that incorporates much of the content of this module in order to give you a sense of how it would apply to a refugee with a disability:

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.

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.

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.

Displayed on the screen are the sources used in the module.

Thank you for completing PRIDE Provider Module 1. Special thanks to Barry Taylor of Equip for Equality, a PRIDE partner, for narrating part of this module.