Evolving Towards Equity Q3 Reading

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UNLEARNING & RE-THINKING

All of us learn about disability in different ways. As we've previously explored through earlier sections of *Evolving Towards Equity*, many of these ways of thinking are problematic and often harmful. To-date, the *Evolving Towards Equity* trainings have centered around conceptual models of disability. Conceptual models of disability are mental frameworks that inform (even unintentionally) how we think about disability and how we act towards people with disabilities.

In this Quarter 3 Reading, we will begin by learning about the Rehabilitation and Expert-Professional Models of disability. These models of disability are especially closely tied to the work that organizations like Lifeworks do, so a disclaimer is offered here that this might be difficult content for you to get through at times.

That being said, it is important for us to critically and intentionally unpack the Rehabilitation and Expert-Professional Models, because of the often-unequal power imbalance that exists between people with disabilities and non-disabled people – especially those who are deemed "experts" or "professionals." This Q3 Reading will also draw the connections to how these common models of understanding disability also tend

to diminish the diverse individual identities of people with disabilities and has the capacity to decrease personal autonomy and agency of the people we serve.

REHABILITATION MODEL OF DISABILITY

Remember that conceptual models of disability have primarily emerged from people with disabilities communicating about their own lived experiences of moving through society with a disability. Because of that, learning the different models of disability can help us center the voices and perspectives of people with disabilities themselves.

The Rehabilitation Model is an off shoot of the Medical Model of disability (for a refresher on the Medical Model, see the *Evolving Towards Equity* Q2 Reading.) The Rehabilitation Model has been described as a mindset that regards the person with a disability as in need of services from a rehabilitation professional who can provide training, therapy, counseling or other services to make up for the "deficiency" caused by the disability.

In historical context, the Rehabilitation Model gained acceptance in the U.S. after World War II when many disabled veterans needed to be re-introduced into society (even though there have always been people with disabilities in society, long before the World Wars of the 20th century.) Furthermore, the current Vocational Rehabilitation system is designed according to this model.[1]

Remember back to our previous training on the Medical and Charity Models. The Medical Model of disability – in its belief that disability is something to be cured or fixed about an individual's body or mind – "ignores the ability of many individuals to live full and successful lives and to be independent."[2] It is important to note here that for this and other reasons, people with disabilities have been very critical of not only the Medical Model, but also the Rehabilitation and Expert-Professional Models.

When thinking under the Rehabilitation Model, one typically believes that "care and support are to be determined [solely] by professionals."[3] The Rehabilitation Model differs slightly from the Medical Model; however, in that Rehabilitation Model makes the assumption that "if the person with a disability makes an effort and works with

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[1] National Black Disability Coalition. "Disability Models." Available online at: http://www.blackdisability.org/content/disability-models.
[2] Smeltzer, S.C. 2007.
[3] Smeltzer, S.C. 2007. "Improving the health and wellness of persons with disabilities: A call to action too important for nursing to ignore. *Nursing Outlook* 55: pp. 189-195. Available online at: https://nisonger.osu.edu/media/bb_pres/marks_11-12/handouts/Handout%205%20-%20Models%20of%20Disability%20(Smeltzer).pdf.

rehabilitative services, they can 'overcome' their disability."[4] This belief that disability can and should be "overcome" is one that is still very common in our society today, and it is one that many advocates and self-advocates believes needs to be challenged. The Rehabilitation Model is commonly rejected by people with disabilities and other advocates because of this, and also because the Rehabilitation Model's approach "often fails to consider the reality of permanent disability."[5]

EXPERT-PROFESSIONAL MODEL OF DISABILITY

The Expert-Professional Model is another offshoot of the Medical Model. Within its framework, those who are designated as 'professionals' follow a process of identifying the impairment and its limitations (using the Medical Model), and then take the "necessary action to improve the position of the person with a disability."[6]

This, as many people with disabilities have expressed themselves, has the potential to produce a system through which an "authoritarian, over-active provider of services can prescribe and act for a passive client."[7] The National Black Disability Coalition goes on to describe the Expert-Professional Model of disability in this way:

> This relationship has been described as that of fixer (the professional) and fixee (the client) and clearly contains a power dynamic and inequality that limits partnership and collaboration. Although a professional may be caring, when solutions are imposed on someone else, the resulting outcome may not be equally beneficial for all parties. If the decisions are made by the "expert," the client has no choice and is unable to exercise the basic human right of freedom over his or her own actions. In the extreme, this can undermine the client's dignity by removing the ability to participate in the simplest, everyday decisions affecting his or her life.[8]

The unequal power dynamic which is exposed in the Expert-Professional Model also creates an environment where **paternalism** is all too commonplace.

Drawing Connections to Our Work

Whether we view ourselves as dominant or not, the reality is that our role as service providers has historically put us in positions of power over people with disabilities. As we

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[4] University of Illinois, University Library. 2020. "Disability Theory: Medical/Rehabilitative Model." Accessed online at: https://guides.library.illinois.edu/disabilitytheory.
[5] Smeltzer, S.C. 2007.
[6] National Black Disability Coalition. "Disability Models." Available online at: http://www.blackdisability.org/content/disability-models.
[7] National Black Disability Coalition. "Disability Models."
[8] National Black Disability Coalition. "Disability Models."

will discuss in later sections of this reading, the oppressive system of ableism seeks to maintain that power and authority, and is operating in and around our sector, again, whether we choose to recognize it or not.

Many of the people in our industry who are designated as "experts" or "professionals" are non-disabled, or people without disabilities. Being a member of a dominant identity group in our sector (being a person without a disability, or being perceived as non-disabled), often grants us more access to resources and control over our own lives. The impact of all this is that bias, power, and privilege distorts relationships and sets the standard for non-disabled people "having superior judgment" (crucial to the supporting of and maintenance of ableism.)

Ed Roberts, one of the most influential disability rights leaders in the United States history, detailed how this impacts the disability services system:

> "The whole system was set up this way. The counselors are good at making decisions for people instead of throwing the power back to the consumer, saying 'What do you want? Let's see if we can make it a reality.' We have to put the choices back in their lap. Service professionals who work with disabled people have to make this into an art form. **People come to you and expect to be told what to do. It's your job to place that power back into their hands**. You are there to help them find out what they want to do, not to decide what you think is best for them."[9]

If we, as service professionals (or as fellow community members and neighbors of people with disabilities), do not intentionally shift the power of choice to people with disabilities, then we likely contribute to (rather than confront and/or counteract) the reality that people with disabilities' needs, desires, diverse experiences are diminished in most settings.

INTERSECTIONALITY & DISABILITY AS IDENTITY

Intersectionality

First coined by Black feminist legal scholar Kimberlé Crenshaw in 1989, intersectionality made its way into the Oxford English Dictionary in 2015. **Intersectionality** is "the complex, cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism, classism, [and ableism]) combine, overlap, or intersect especially in the experiences of marginalized individuals or groups."[10]

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[9] Roberts, Ed. "On Disability Rights: Highlights from Speeches by Ed Roberts." *CommonLit*. Available online at: https://www.commonlit.org/en/texts/on-disability-rights-highlights-from-speeches-by-ed-roberts.

[10] Merriam-Webster. "Intersectionality." Accessed online at: https://www.merriam-

In other words, even individuals who belong to the same social group or category – for example, two people who identity as women – *experience social structures very differently based on their other overlapping social identities*. In this example, let's imagine that of the two women, one identifies as white, as part of the LGBTQ+ community, and as a person with a disability. The other identifies as Black, as a Muslim, and as an immigrant to Minnesota. The different intersections of these two women's identities mean that they experience discrimination and "-isms" very differently, even though on they both share the same category of identity of "women."

For nonprofits and disability service providers, it is crucial that we remember that the people with disabilities who we serve have other aspects of their social identities, just like non-disabled people. This means that people we serve who identify as Black, also experience racism. This means that people we serve who identify as women also experience sexism. This means that people we serve who are low-income also experience classism. Disability is another part of individuals' identities, and it is important to explore disability as an identity category.

Disability, as an identity category or social group, is the most intersectional of all minority groups. This is because disability is one of the only identity groups that any person, regardless of age, race, gender identity, ethnicity, religion, sexual orientation, class, education, etc. can join at any time in their life. Disability does not discriminate.

DISABILITY AS IDENTITY

As disability service providers and professionals, we are likely all very aware of the notion of **person-first language**, and that some people with disabilities have a preference for person-first language. Throughout history, people with disabilities have been referred to in extremely dehumanizing ways. For example, people with intellectual disabilities have been called – even in official records – "morons," or "imbeciles." It should make sense then, if you were de-humanized and referred to as one of these terms, that you would want to be viewed and recognized for your humanity first, then your disability.[11]

However, it is also important to recognize that there are other people with disabilities who prefer **identity-first language**. As an identity category, disability does not merely describe an individual body or mind, but membership within a wider cultural group. Some specific disability communities, such as Autistic and Deaf communities, will primarily use identity-

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webster.com/dictionary/intersectionality.

[11] Callahan, Molly. July 12, 2018. "'Autistic Person' or 'Person with Autism': Is There a Right Way to Identify People?" *News@Northeastern*. Accessed online at: https://news.northeastern.edu/2018/07/12/unpacking-the-debate-over-person-first-vs-identity-first-language-in-the-autism-community/.

first language, and may prefer not to refer to themselves as disabled at all. See the table below for examples of the differences between person- and identity-first language.

Person-first Language	Identity-first Language
She is a person with a disability.	She is a disabled person.
Person-first Language	**Identity-first Language**
They are a person with autism.	They are an autistic person.

Although person-first language is still considered the best option to default to if you do not know the preference of the person themselves, it is still important to understand and acknowledge the significance of why some people with disabilities prefer identity-first language. Many believe that when we affirm disability as an identity it "positions the individual to personally identify as disabled, by their own choice, rather than being told they are disabled by an external (usually non-disabled) 'authority.'"[12]

WHAT IS ABLEISM?

Defining Ableism

In the words of disability justice advocate Azza Altiraifi, "ableism is a system that is designed, at its core, to categorize and rank bodies and minds as either normative or deviant, as valuable or disposable, and as productive [or burdensome]."[13] The Social Model of Disability will be discussed further in the next *Evolving Towards Equity* reading, but disabled authors and activists have asserted that when we analyze disability through the lens of the Social Model, disability, like sexism and racism, can be interpreted as "discrimination and social oppression." Ableism is just one of many manifestations of discrimination and social oppression. In short, **ableism** is a set of practices and beliefs that assign inferior value to people who have disabilities. An ableist can be defined as someone who treats non-disabled individuals as the standard of "normal living." Ableism has also been defined in this way:

> Ableism is the devaluation of disability that results in societal attitudes that uncritically assert that it is better for a child to walk than roll, speak than sign, read print than read Braille, spell independently than use a spell-check, and hang out with non-disabled kids as opposed to disabled kids.[14]

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[12] People with Disability Australia. "Identity-first Vs Person-first Language." Available online at: https://pwd.org.au/resources/disability-info/language-guide/identity-vs-person/.

[13] Altiraifi, Azza. April 14, 2020. Georgetown University Disability Studies Program's Webinar on "Dismantling Settler Colonialism and Ableism: Disability Justice and Decolonization."

[14] T. Hehir (2002), quoted in Nario-Redmond, Michelle R. 2020. *Ableism: The Causes and*

Ableism as a term and as an idea "emerged out of the disability rights movements in the United States and the United Kingdom to serve as a parallel to sexism and racism for those who were studying disability as social creation."[15]

Individual Ableism

Ableism manifests in many ways, including at the individual or interpersonal levels. This can include, but is not limited to, individually held attitudes, biases, and prejudices. These attitudes, biases and prejudices then inform individual thoughts and expressed actions or behaviors. Whether we acknowledge it or not, everyone has biases and relies on stereotypes to categorize and make assumptions about people and groups. Attitudes and biases (conscious or unconscious) that individuals often hold towards people with disabilities can range from: pity, hostility, fear, paternalism, or compassion.[16]

Internalized Ableism

The impacts of ableism hurt everyone – but no group more than people with disabilities. Ableist messages, words and actions are hard *not to* internalize, and negatively impact the sense of identity, self-image, and self-worth of many people with disabilities. That's how oppression works. Because problematic messages are reinforced consistently and in so many different areas of life, people with disabilities are forced to work hard to not internalize the things they are told about themselves their whole lives.

Because of ableism and rigid social standards of how humans are "supposed" to act, produce, move, behave, etc., people (disabled and non-disabled) are rewarded for conformity. This means we act and make decisions (intentionally or unintentionally) based on wanting to be valued while existing within these rigid social codes and ableist systems. In short, ableism negatively affects us all, but it most deeply affects people who are the most impacted by injustice and oppression.

UNDERSTANDING ABLEISM AS SOCIAL OPPRESSION

Although it is important to examine our own individual attitudes, assumptions, and actions, ableism does not just exist at the individual level. Ableism also exists in our institutions and in our social systems at-large, which is reflected in the ongoing and persistent disparities in social outcomes between people with disabilities and non-disabled people.

Institutionalized ableism becomes apparent when dominant, non-disabled society does

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Consequences of Disability Prejudice. p. 5.

[15] Nario-Redmond, Michelle R. 2020. *Ableism: The Causes and Consequences of Disability Prejudice*. p. 5.

[16] Nario-Redmond, Michelle R. 2020. *Ableism: The Causes and Consequences of Disability Prejudice*. p. 17.

not seem to think too critically – or has historically not seemed to care – about persistent social inequalities between disabled and non-disabled people in terms of educational attainment, employment status, socioeconomic status, and many other areas.[17] People without disabilities are two times more likely to attend college, and two times more likely to be employed than people with disabilities. Disabled people make approximately $28,000 less per year and are more than two times as likely to live below the poverty line.

Disability Disparities Data[18]

- Educational Attainment: 15% of people with disabilities have a BA or higher, compared to 30% of people without disabilities.
- Employment: 37% of people with disabilities are employed vs people without disabilities who are employed at a rate of 80%.
- Average Household Income: is $46,900 per year for people with disabilities vs $74,400 per year for people without.
- Poverty: 26% of people with disabilities live below poverty line vs only 10% of people without.

Disability Allyship

An ally is willing to take action in support of another person, in order to remove external barriers that impede that person from contributing their skills and talents in the workplace or community. Learn more about disability allyship in the following sections and how you can apply what you've learned in this module to take action, to be a part of history moving forward, and most importantly, to be an ally to the people we serve every day.

TAKE ACTION! ALLYSHIP IN PRACTICE

Introduction

Even amongst disability service providers and support professionals, disability inclusion is not a topic many are proficient in. A large part of this is due to systemic exclusion which has resulted in minimal exposure and experience living and working alongside people with disabilities equitably. Together, we need to move past the assumption that because we support people with disabilities, we are automatically disability inclusive.

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[17] *Ibid*. p. 6.

[18] Taken from data gathered Nationwide in 2017-2018 for the American Community Survey. More data accessible online at: https://disabilitycompendium.org/sites/default/files/user-uploads/2018_Compendium_Accessible_AbobeReaderFriendly.pdf.

Eliminating Barriers & Ableist Systems

It is human nature for us, regardless of lived experience, to avoid topics that are that challenging or to be submerged in this type of subject matter. In the modern disability services industry, we often talk about being "person-centered" or taking "person-centered approaches" – but we often fail to recognize that we *have to* incorporate an understanding of social systems, and how they impact people, in order to be truly person-centered. Pretending that people with disabilities exist in a 'parallel universe' – as in they are not subject to other "-isms" – is a catastrophic misstep on the part of many disability service professionals. Ableism exists within and depends on other systems of oppression, such as racism, sexism, classism, etc.

We won't be able to 'help' people if we can't acknowledge the existence of systemic oppression. If we don't take the responsibility for understanding these systems, then it is impossible for us to do what we set out to do when we joined this industry. If we as professionals are people who are supposed to be advocating for people with disabilities, then we must try to understand how the world interacts with them, not just how people with disabilities interact with the world.

Personal Bias, Power & Privilege

In order for us to achieve systemic change, it is crucial for us to recognize how we contribute as individuals to those systems which operate around us. As we know, personal bias is a factor that influences every person's worldview, perspectives, decisions and actions. A bias is "a tendency, inclination, or prejudice toward or against something or someone."[19] We all have bias that we need to acknowledge. Bias is often built on stereotypes "rather than actual knowledge of an individual or circumstance, [which] can result in prejudgments that lead to discriminatory practices."[20] When unchallenged, bias can permeate service delivery, having a detrimental impact on the lives of the people we support.

CHANGING MINDSETS & USING NEW APPROACHES

Changing our Mindset

Previous iterations of service delivery through the decades (influenced by charity, medical, rehabilitation, and expert-professional models) have contributed to deep disparities between people with disabilities and non-disabled people in the U.S. This was not an accident.

We have said (with our actions, if not exactly with our words) for hundreds of years: We're going to need of all of these different types of professionals to "handle and manage" all of

[19] Psychology Today. "Bias." Available online at: https://www.psychologytoday.com/us/basics/bias.
[20] *Ibid.*

"those people." Society has essentially told people with disabilities for decades that they cannot (and should not) be in the community. The delivery of services might have changed, but non-disabled people kept saying and demonstrating this again and again in different ways.

When groups have been intentionally marginalized, there is a legacy that carries on. This legacy ties to people's self-worth and dignity and societal perceptions. Think about how you would feel if, for most – if not all – of your life, through words and actions you were told that "you can't, and you won't, exist in the community." That's what many people with disabilities have been told through the words and actions of community.

All this said, and after reading through history and models of disability, what do we, as disability service professionals, need to do differently going forward? What is our obligation as a service provider to build people up after all these years of tearing them down? We need to own our history and our role moving forward. In doing so, we must recognize our role and the power dynamics at play, while utilizing new approaches and new mindsets.

Using New Approaches

One of the most important actions we need to take moving forward, when envisioning truly inclusive communities and workplaces, is to remember that when we talk about including "all people," that means *all people*. Community is for everyone.

But, rather than advocate for the community to be inclusive, historically many disability service providers have contributed to and upheld the status quo—meaning we ourselves have co-signed onto the notion that there are certain "types" of people with certain "types" of disabilities who just can't be included in the community. Essentially, society has created a hierarchy of who is worthy of being included or not, and we basically "pick" people who "get" to fit into the world as it's been created, rather than recreate the communities in which we live to fully and equitably include everyone.

The following are commonly used examples today as reasons to justify the continued legacy of segregation and reasons to not evolve towards equity. In many situations, they have also been the sole reason to keep individuals with disabilities from living, working, or existing where and how they want to be. These are also examples of ableist social norms. By continuing to co-sign onto these status quo norms, disability service providers and professionals are enabling inequity to persist. What could our communities look like if we truly believed (and proved by our actions that we believed) these statements listed below?

- **Toileting**
  - Oppression Mindset
    - "Attending that event is not an option for Ashley because she cannot go to the bathroom independently."
  - Liberation Mindset
    - There are no support needs/physical care needs too great that justifies the segregation of disabled people.
- **Behavior**
  - Oppression Mindset
    - "Working is not an option for Alli because she expresses her emotions loudly."
  - Liberation Mindset
    - There's no emotional or physical expression or response that justifies the segregation of disabled people.
- **Equipment**
  - Oppression Mindset
    - "Though she doesn't need the level of staffing, living independently is not an option for Ashley because she needs ramp access."
  - Liberation Mindset
    - There's no accessibility need (lifts/ramps) that justifies the segregation of disabled people.
- **Productivity**
  - Oppression Mindset
    - "Alli can't work for minimum wage because she doesn't complete tasks fast enough."
  - Liberation Mindset
    - There is no rate of capital gain that justifies the segregation of disabled people.

In order for our communities to be inclusive, we need to plan for those who have been the most left out and the most excluded. The many barriers that people with disabilities face are real, however we need to approach them with solutions rather than passivity. This does not mean that we need to stop talking about different levels of support needs – every single person is interdependent with others in order to thrive. But this does mean we must use new approaches – like the Social Model and Disability Rights Model (which we will learn more about in Quarter 4 of *Evolving Towards Equity*) – to build an inclusive community that centers the historically most written-off people. If we really want to make things different, we cannot take the legacy of segregation into the future.

THANK YOU

Thank you for reading Quarter 3 of Lifeworks' *Evolving Towards Equity* training series. In Quarter 4, we will dive into the Social and Disability Rights Models, as well as topics such as allyship, social inequality, and ways to take action moving forward towards equity.

Make sure to connect with your supervisor and teams about what you learned from this Quarter's reading and the *Evolving Towards Equity* training videos.

We appreciate your dedication and commitment to the work we do and the people we serve at Lifeworks.