PROGRESSIVE PERSON-CENTERED THINKING:
TOOLS TO EVOLVE TOWARDS EQUITY

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Overview

When it comes to creating equitable communities, change can be hard, but must happen in order to move forward. This module, the Evolving Toward Equity trainings, facilitated team discussions, and additional reading materials will explore how we as service providers can actively explore our bias toward protecting or directing people with disabilities to do what we think is best for them. We make decisions for people all the time and within our current culture, we should be aware of our position of power and influence over peoples' lives. We often decide *for* people and take away their opportunity to make their *own* choices. Our role as service providers has historically put us in positions of power over people with disabilities. In our field's recent past and still today, service recipients have been seen and labeled as needing people without disabilities in order to succeed. This notion is untrue and needs to be removed from how we think about, plan, and deliver services.

While the training requirements mandated by licensing have contained content about person centered services for decades, this module is intended to support our evolution toward services that champion not only "Important To and Important For" people, but more importantly, champions the voices of people with disabilities as the primary authority to define the standards of support within human service organizations. Since the inception of the disability services industry, person-centered thinking has evolved, but unfortunately, the voices of people with disabilities have been excluded from the development of implementation standards within human service organizations.

It is the intent of Lifeworks to incorporate several other critical areas of person-centeredness into trainings that support our philosophy of service delivery. These areas include history of disability rights, dignity, culture, self-determination, personal advocacy, and self-sufficiency. Lifeworks' Progressive Person-Centered Thinking Module explores historical and contemporary perspectives and infuses our person-centered service philosophy of self-determination with the work of disabled activists. Lifeworks is committed to co-creating planning tools and resources alongside people with disabilities.

Lifeworks Values & Philosophy

In 2019, Lifeworks began a project to take a deep look at who we are with the intent of refining our values in a way that expresses what's important, sets us apart, and guides our decision making. Our values are the blueprint for our success.

Lifeworks Values

1. <u>You Lead the Way – We Listen</u>
   We honor choice and pursue opportunities with community at the heart of our work.

2. <u>Together, We Break Down Barriers</u>
   We seek diverse perspectives, advance accessibility, and encourage a sense of belonging for all.

3. <u>We Focus on Impact</u>
   We hold ourselves to the highest standards. We share expertise and collaborate to find solutions that address the whole picture.

4. <u>We Reinvent What's Possible</u>
   We take chances and welcome the unknown. We learn from the past and lean into the future.

Self-Direction & Self-Determination

Part of Lifeworks' philosophy is that person-centered thinking is an attitude, a belief, a value and a feeling of being respected. It acknowledges that all people have the right to be included and valued. Lifeworks believes that people should have positive control over their lives. Lifeworks promotes maximum participation in the environments of the person's choice. Lifeworks centers personal growth and the dignity of all the persons the organization serves.

Self-determination means that all people have the right to direct their futures; have control over how they live their lives, where, and with whom; and have authority over the resources

that support them. We recognize that historically, people with disabilities have been denied their right to self-determination, and have "often been overprotected and involuntarily segregated, with others making decisions about key elements of their lives, [which has] inhibited their ability to become contributing, valued, and respected members of their communities, living lives of their own choosing."[1]

Lifeworks promotes the four principles of self-determination, *Freedom*, *Authority*, *Support* and *Responsibility*. Lifeworks uses these principles throughout the design and delivery of our services and business management practices. Understanding of and commitment to these principles are essential to ensure the basic human right of self-determination is respected.

1. <u>Freedom</u>: The exercise of the same rights as all citizens. People with disabilities, with assistance when necessary, will establish where they want to live, with whom they want to live and how their time will be occupied. They do not have to trade their inalienable rights guaranteed under the Constitution for supports or services.
2. <u>Authority</u>: The control of whatever sums of money are needed for one's own support, including the re-prioritizing of these dollars when necessary. This is accomplished through the development of an individual budget that "moves" with the person.
3. <u>Support</u>: The organization of these resources as determined by the person with a disability. This means that individuals do not receive "supervision" and "staffing". Rather, folks with disabilities may seek companionship for support and contract for any number of discrete tasks for which they need assistance.
4. <u>Responsibility</u>: The wise use of public dollars. Dollars are now being used as an investment in a person's life and not handled as resources to purchase services or slots. Responsibility includes the ordinary obligations of American citizens and allows individuals to contribute to their communities in meaningful ways.

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[1] American Association on Intellectual and Developmental Disabilities (AAIDD) & The Arc. 2018. "<u>Joint Statement on Self-Determination</u>."

Person-Centered Thinking in Context

40 Years of "Person-Centered" Thinking

1980s	• Getting to Know You • Personal Futures Planning
1990s	• PATH/MAPS • Five Valued Experiences
2000s	• A Picture of a Life • Discovery
2010s	• Important To/Important For • 245D
2020s	• Progression Tool • Community Mapping

The Positive and Negative Outcomes of Early Person-Centered Thinking

Positive Outcomes

Person-centered thinking intentionally challenged the historically accepted norm of dehumanizing people with disabilities. Emerging between 1979-1992,[2] there was an eruption of tools seeking to disrupt many long held social norms. The spirit of person-centered thinking and planning was about problem-solving and trying new approaches. This spirit of person-centered practices inspired many well-meaning professionals to come together, leading some to recognize that their current practices did not always work in favor of people with disabilities. In addition, early person-centered philosophy leaders and thinkers began the necessary legacy of thinking about and questioning disability service professionals' roles, and the influence that they carried. The early work has shown us the importance of not only tools, but resources and supports designed to change people's perceptions of disability inclusion and what is possible. Though there is no person-centered tool that can fix bias, we have the opportunity to evolve and hold each other accountable for how we do our work.

Negative Outcomes

However, there were also negative unintended consequences of person-centered thinking and planning. The focus was nearly always on fixing people, emphasizing that there were (non-disabled) people who needed to be trained as professionals in order to fix people with disabilities. One of the major pitfalls of person-centered thinking and planning is that "*any*

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[2] O'Brien & Lyle-O'Brien, 2000.

'person-centered' approach can be used in an *agency-centered* or *system-centered* way."[3] Many person-first initiatives manifested as delays in allowing people to gain control over their lives. Early approaches centered around non-disabled experts and their elaborate processes to overcoming their own biases. In doing so, people with disabilities weren't included in the development of the tools, nor the design of the person-centered planning process itself.

Perhaps most importantly, nothing about these early approaches seem to be grounded in the reality that the broader community is the problematic barrier. Person-centered planning and thinking have not traditionally been about significant transformation of the community, including the evolution of disability service providers. Consider how different the outcome could be if we chose to frame our work with the mindset of the second question, instead of the first:

- "How can we help you conform so you can access the inaccessible community?"
- "How can we address the ways our community was built to be inaccessible and exclusionary rather than inclusive of all people?"

Over the decades, there   documented evidence to support how person-centered planning can be misinterpreted, or misused, resulting in observations from disability professionals such as the ones below:

- "The fact that many professionals continued to defend institutions and advocate for congregate services and segregated special education opened deep questions about the legitimacy of the professional perspective."[4]
- "It is possible for well-meaning professionals to destroy lives by telling stories."[5]
- "The contrast grew between people's potential with good assistance and the lives that too many people were forced to live by professionals who would rather attribute incompetence to people with disabilities than face what they themselves did not know how to do."[6]

The ability to think critically about our contributions to how the community views people with disabilities is a challenging and necessary step in evolving towards equity. Though we may not intentionally see ourselves as experts or authority figures, the founder of the

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[3] Institute on Community Integration's Research and Training Center on Community Living, University of Minnesota. 2012. "Person-Centered Thinking."
[4] Lyle O'Brien, Connie & John O'Brien. 2000. "The Origins of Person-Centered Planning: A Community of Practice Perspective."
[5] Blatt, Burton 1981. Quoted in Connie Lyle O'Brien & John O'Brien. 2000. "The Origins of Person-Centered Planning: A Community of Practice Perspective."
[6] Lyle O'Brien, Connie & John O'Brien. 2000. "The Origins of Person-Centered Planning: A Community of Practice Perspective."

Independent Living Movement, Ed Roberts, once said about disability service professionals: "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."[7] We now turn to how we can begin to live out this vision as employees of Lifeworks.

Challenging Perceptions about Disability

Disability has always been a natural part of human diversity. However, rarely in history has our society viewed disability as "normal." We view it as completely the opposite—as abnormal, or as something to be feared or pitied. In recent decades, society has slowly evolved toward recognizing the full humanity of people with disabilities because of the activism and advocacy of people with disabilities. Parts of our society have moved on from thinking that people with disabilities are only recipients of charity and pity, or that they should be "cured" through medical professions. Now, many are starting to think about social and human rights models of disability, analyzing societal barriers placed in the way of people with disabilities as they seek full equality and full community inclusion.

Models of disability (shown below), created by people with disabilities themselves, have helped society frame and understand disability (in both positive and negative ways). Historically, the medical and charity models have been the most common ways non-disabled people have understood disability. One big question we need to ask ourselves is: even though our ways of thinking about disability have evolved and progressed, have disability programs and services progressed in the same way or at the same pace?

The social model of disability was revolutionary. It switched the 'problem to be solved' from being within the individual with a disability, to the 'problem to be solved' being within societal stigma and barriers to inclusion. The social model of disability flipped the typical narrative—for the very first time, it provided people with disabilities "a framework for recognizing that many of the challenges they faced rested with the decisions and actions of society, and not with themselves."[8] The ways in which we as professionals and our organizations (even unintentionally) reflect the different models or perceptions of disability, strongly influence the philosophies behind (and the delivery of) the work we do.
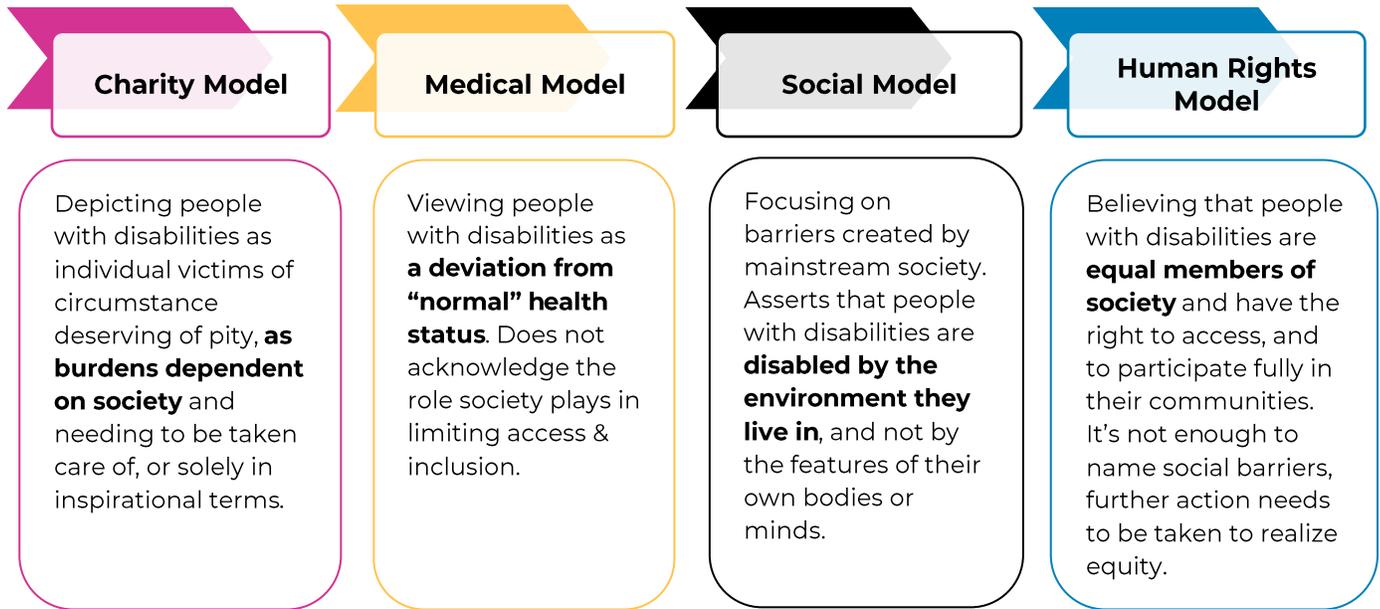
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[7] Minnesota Governor's Council on Developmental Disabilities. *Parallels in Time*.
[8] Disability Advocacy Resource Unit. "How the social model paved the way for the human rights model." Available online.
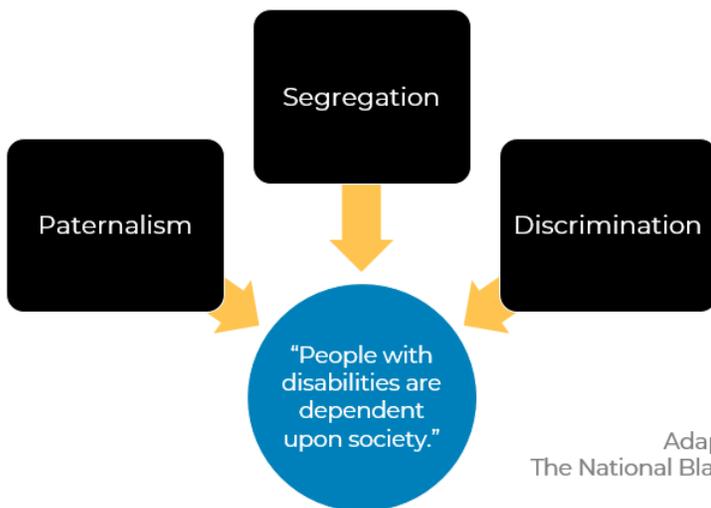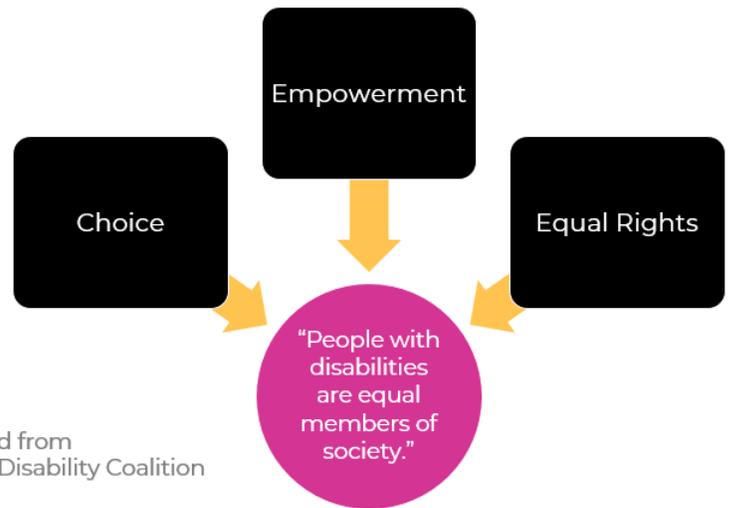
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Conceptual Models of Disability

Charity Model	Medical Model	Social Model	Human Rights Model
Depicting people with disabilities as individual victims of circumstance deserving of pity, **as burdens dependent on society** and needing to be taken care of, or solely in inspirational terms.	Viewing people with disabilities as **a deviation from "normal" health status**. Does not acknowledge the role society plays in limiting access & inclusion.	Focusing on barriers created by mainstream society. Asserts that people with disabilities are **disabled by the environment they live in**, and not by the features of their own bodies or minds.	Believing that people with disabilities are **equal members of society** and have the right to access, and to participate fully in their communities. It's not enough to name social barriers, further action needs to be taken to realize equity.

Charity & Medical Model of Disability   vs.   Social & Human Rights Model of Disability

Oppression Mindset

Paternalism

Segregation

Discrimination

"People with disabilities are dependent upon society."

Liberation Mindset

Choice

Empowerment

Equal Rights

"People with disabilities are equal members of society."

Adapted from
The National Black Disability Coalition

In Practice

Skills & Expectations

Progressive person-centered thinking requires us to challenge our own beliefs. Like many tasks and responsibilities in the workplace, our priority is to continuously make improvements to the quality of our work. In doing so, we need to reflect on our contributions to the oppression or the liberation of people with disabilities. In order for us to truly support disability inclusion and center those we support in our service delivery, together we must commit to supporting one another and co-creating a culture where innovation, removing barriers and accountability are the goals. This would mean that the people we serve feel like they are free to be their whole, intersectional selves, and know that they are in control of their lives. Coined by Kimberlé Crenshaw, intersectionality describes the complex and cumulative way in which the effects of multiple forms of discrimination (such as racism, sexism, classism and ableism) overlap or intersect, especially in the experiences of marginalized individuals or groups.[9]

Putting Person-Centeredness into Practice

So, what does this mean for day to day interactions? Below are some examples of common occurrences where we have the opportunity to decide how we show up service provider professionals and influence situations by leveraging the circumstances in which we have power and privilege to use as a resource to break down barriers and disrupt ableism, which is defined as the "practices and dominant attitudes in society that devalue and limit the potential of persons with disabilities. A set of practices and beliefs that assign inferior value to people with disabilities."[10]

Support Team Meeting Facilitation: Though according to licensing, team meetings are intended to be about what a person wants, often they become gatherings where a person with a disability has "a vote" versus "the final say." To avoid this, we must believe in the social and human rights model which states that people with disabilities are equal members of society and they are the experts of their own lives. Refer to the planning module. Reach out to your supervisor for support and suggestions.

Informed Choice: Our role is to provide information so people can make their own decisions, but what if we don't truly trust their judgment? In regard to informed choice, we must first believe that people with disabilities *do not* have inferior judgment. This begins with the recognition of how consistently the belief that

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[9] Crenshaw, Kimberlé. 1989. "Demarginalizing the Intersection of Race and Sex: A Black Feminist Critique of Antidiscrimination Doctrine, Feminist Theory and Antiracist Politics," *University of Chicago Legal Forum*. Available at: http://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8.
[10] *StopAbleism*. Accessed online at: http://www.stopableism.org/p/what-is-ableism.html.

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people with disabilities have inferior judgment has been reinforced in our communities. We need to reckon with the idea that our role is to provide information and support decisions that are made, rather than try to convince or coerce people into the decision we think they should make.

Navigating Resistance: Often there are moments when a team or community member is not comfortable with the ideas or decisions a person with a disability has. Though consensus is ideal, our role is not centering the comfort of non-disabled people on the team. A helpful approach in these situations, is reminding ourselves that removing barriers is a necessary step in people being able to take risks and experience life. In addition, helping people understand that bias and beliefs are historically the most significant barriers to people with disabilities living included lives is a truth that needs to be told. Reach out to your supervisor for support and suggestions. Do work ahead of the meeting to anticipate some of the questions and concerns that may come up in the discussion to have a prepared response.

- Licensing Documentation: Too often the goals in place for a person are written with the intention of conforming to social codes like politeness, timeliness or behavior, rather than focusing on what the person wants for their own life. Though we know there are certain expectations within different contexts, we must also acknowledge that people with disabilities have effectively been segregated from mainstream norm-setting, meaning they haven't been part of making the social rules. It should never be our role to encourage social conformity, but rather support a person in their journey to living authentically as well as working to make our communities more inclusive.

- Social Inclusion: Our communities look to people in roles like ours to take their cues for how to interact with people with disabilities. Arguably one of the most crucial responsibilities in our work is how we role model authentic interactions with the people we support for community members. We must do everything we can to get out of the way of natural and authentic connections, while being mindful of avoiding the stereotype that people with disabilities need a person *without* disabilities to watch, guide, or care for them. This sends the idea that people with disabilities are dependent on society, instead of the truth, which is they are equal members of society. The way we model disability inclusion should not stop when we are not directly working with the people we support – this goes for staff meetings, email conversations, Zoom interactions, etc. Modeling disability inclusion isn't something you have to turn on and off. Supporting disability inclusion is modeling these behaviors in all your relationships and interactions to offer an inclusive lens for everyone you know in all areas of your life.

When faced with obstacles that arise when supporting people with disabilities, we don't need to take the most common, path of deciding that disability is the reason why something cannot be done or accomplished. Instead we must always listen to the person facing the obstacle and ask ourselves and others:

1. What are the external barriers?
2. What has already been tried?
3. What can we do next?

Resource Library

Progression Tool
Branded version of Good Day/Bad Day
Communication Dictionary
Relationship Mapping

Positive Supports Module
https://lifeworksservices.sharepoint.com/:b:/r/sites/DayServices/Shared%20Documents/Supporting%20People%20with%20Positive%20Support%20Strategies.pdf?csf=1&web=1&e=4ZEh8V