A Resource Packet

Advancing Disability Justice in Public Health:

Centering Women of Color with Intellectual and Developmental Disabilities

WITH

Cardea®

INTRODUCTION

This packet includes:

Self-Advocacy Tools

An introduction to eight self-advocacy tools for Women of Color with Intellectual and Developmental Disabilities to use to prepare for and during clinical appointments

Tools for Providers

Three supplemental resources for healthcare providers + access to a **four-module eLearning course** for providers

Training Package

Slide deck presentation, outline, speaker notes, and participant note catcher for organizations to conduct their own internal trainings

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Provider Tools

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Addressing Attitudinal Barriers for Adults with I/DD	5	Guidance for responding to ableism expressed by colleagues or others	Those looking for suggestions to address inequitable approaches and attitudes
Addressing Ableism: Harmful vs Helpful	11	Guidance for language shifts that promote patient respect and autonomy	Those looking for empowering language shifts
eLearning Companion Guide	18	Summary and access to all of the key terms and resources shared in the eLearning	Those looking for reminders on sources for ongoing learning

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Introduction to Self-Advocacy Tools

These eight tools are **patient facing** and meant to support Women of Color with Intellectual and Developmental Disabilities (I/DD) in self-advocating for their needs in clinical appointments, centering their autonomy in healthcare decisions, and resisting systemic barriers based on race, gender, and disability status.

They are applicable and supportive for anyone seeking healthcare guidance or self-advocacy resources. They are all made available digitally, but it may be supportive to have physical copies printed in your place of work for easy access. It also may be supportive to orient an office manager or social worker to these tools, so they are able to recommend them as available resources to patients.

Introduction to Self-Advocacy Tools

In introducing these tools, it is important to meet the patient's learning and communication needs. Work with the patient, their support persons, and any interpreters or other partners in care to ensure full understanding.

Be prepared to work with communication boards, visual communication systems, and Augmentative and Alternative Communication (AAC) devices. Consider adding increased visuals, QR codes to provide audio or visual support, or translation, including ASL, depending on the needs of your patient population.

It's important for staff, support providers, and/or family members or friends to take time to introduce the tool, answer any questions, and repeat as necessary for patient understanding.

Healthcare Self-Advocacy Tools

for Women of Color with Intellectual & Developmental Disabilities

Image courtesy of Dana Chan for Disabled And Here.

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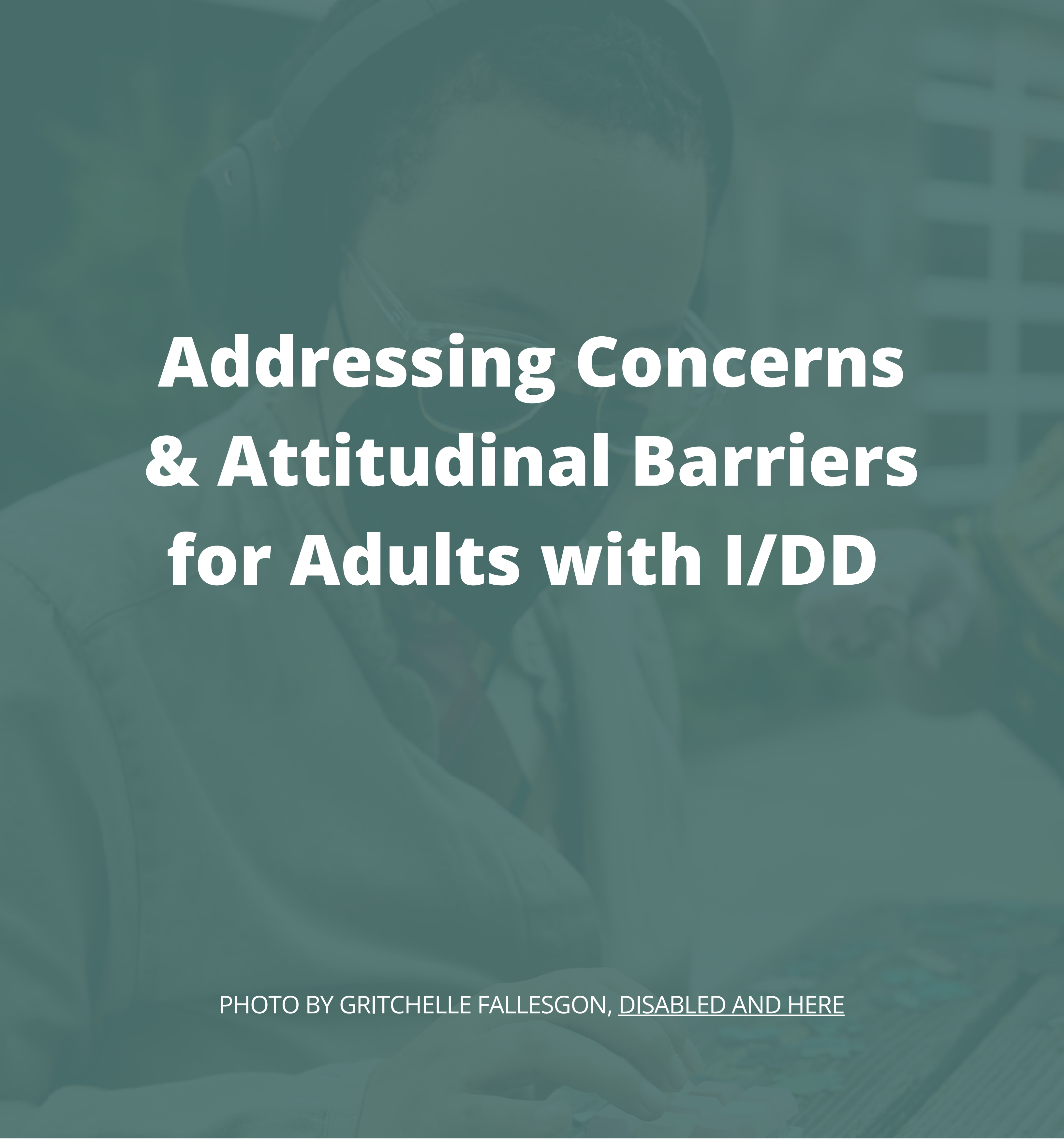
Find the patient facing toolkit here.

Introduction to Tools for Healthcare Providers

The eLearning course, eLearning companion guide, Harmful vs Helpful handout and Addressing Attitudinal Barriers for Adults with I/DD handouts are meant to support you in **developing your own skills** regarding best practices of working with Women of Color with I/DD, as well as **advocating against systemic barriers** that may exist in your workplace and industry.

The eLearning course and all training materials are designed to be relevant regardless of your job title or position and are broadly applicable to a range of healthcare roles and environments.



Addressing Concerns & Attitudinal Barriers for Adults with I/DD

PHOTO BY GRITCHELLE FALLESGON, DISABLED AND HERE

GUIDING PRINCIPLES FOR HARD CONVERSATIONS

Equal Rights and Access

Everyone deserves love, intimacy, and companionship, regardless of disability. Clear health information must be available to prevent harm and promote wellness.

Respect for Autonomy

Disabled adults have the right to make informed decisions about their bodies, relationships, and healthcare.

Parenting Rights

Disabled people can be effective parents and have the right to make their own choices about raising children.

Support for Self-Advocacy

People must be supported in expressing their needs, boundaries, and preferences.

SCENARIOS & RESPONSES

IF YOU HEAR...	POSSIBLE RESPONSES
"This kind of care isn't relevant for my loved one/ this client due to their disability or support needs."	• "Every person, regardless of disability, has the right to understand and participate in decisions about their health." • "Excluding disabled adults from care planning can increase their vulnerability to harm and disempowerment."
"This health information will be too confusing for them because of their communication or cognitive needs."	• "Healthcare must be communicated in ways that are accessible to the individual. Using plain language, visual supports, or other communication aids helps ensure that disabled patients are informed and empowered." • "Supporting understanding is part of ethical, person-centered care."
"They don't need to understand their care because I or a support person will speak for them."	• "While care partners are valuable, adults with disabilities have the right to lead decisions about their own care to the fullest extent possible." • "Developing self-advocacy and communication skills in clinical settings promotes autonomy, dignity, and trust."

SCENARIOS & RESPONSES

IF YOU HEAR...	POSSIBLE RESPONSES
"There are more urgent medical issues—we don't have time for this kind of conversation."	• "Holistic healthcare includes not only treating illness but ensuring patients understand and participate in their care." • "Empowering disabled adults with knowledge about their health supports prevention, safety, and long-term wellness, and helps avoid future crisis."
"This clinic's typical processes won't work for my loved one/this client."	• "We are committed to accessibility and adapting our care delivery. Let's talk specifically about what support would help them feel safe, included, and heard in this space."
"They don't need information about reproductive health because they can't/won't/shouldn't have children."	• "Reproductive health includes far more than pregnancy." • "All people have the right to understand how their bodies work, make informed decisions about their health, and access care without judgment." • "People who are disabled can and do become parents and deserve full information and support around that possibility."

SCENARIOS & RESPONSES

IF YOU EXPERIENCE...	POSSIBLE RESPONSES
Physically guiding, rushing, or touching patients without clear communication or consent. Staff may use physical prompts to move a patient through appointments or procedures, assuming it's necessary or helpful.	• "Let's give [patient's name] the time and space they need to complete this process themselves." • "I'll walk ahead with you so [patient's name] has time to ask any questions they may have." • "We prioritize consent in all aspects of care. Let's use verbal prompts or visual aids instead of physical ones unless the patient explicitly asks for assistance." Always address concerns privately with staff, never in front of the patient, and prioritize direct communication with the patient to honor their autonomy.
Assuming medical information or care instructions are too complex for the patient to understand due to communication or cognitive access needs.	• "People with disabilities have the right to clear, accessible information about their care." • "Let's provide this information using plain language, visual supports, or assistive technology." Practicing self-advocacy and understanding one's own care supports safety, autonomy, and trust, especially when navigating complex systems.

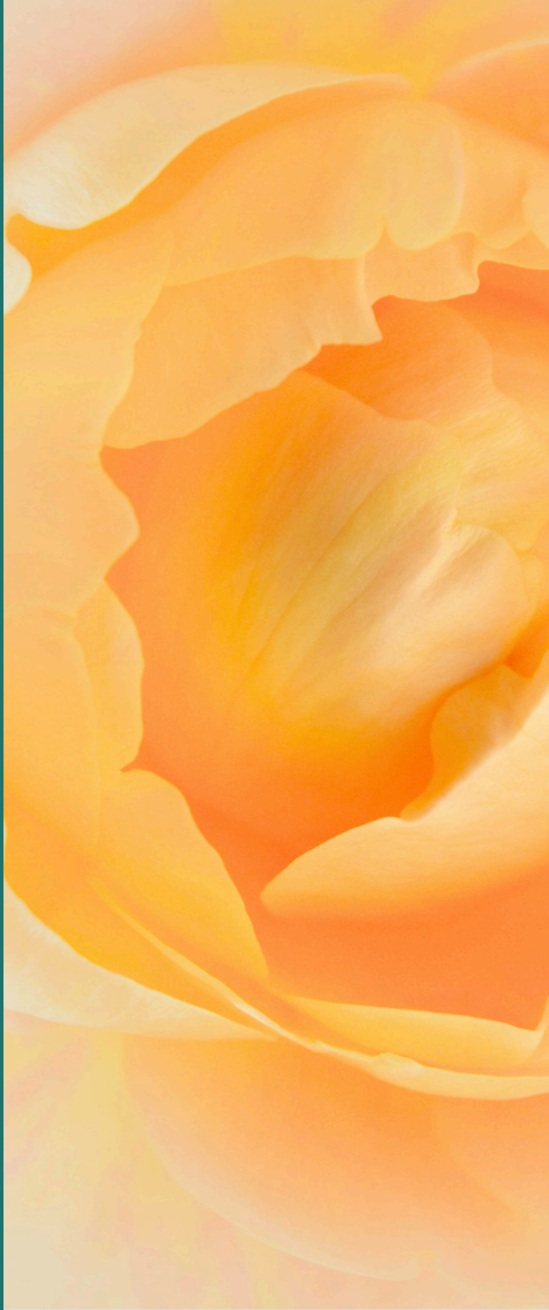
SCENARIOS & RESPONSES

IF YOU EXPERIENCE...	POSSIBLE RESPONSES
Believing that a patient doesn't need information about reproductive health because of assumptions about their capacity or desire to have children.	• "Adults who are disable have the same reproductive rights as anyone else, including the right to parent." • "We must not make assumptions about reproductive choices based on disability status." • "Let's provide the same respectful, factual information we would offer to any other patient." People with disabilities can be and are successful, loving parents. They deserve access to full-spectrum reproductive health information and care.

ADDRESSING ABLEISM:

PHOTO BY DI LAI

HARMFUL VS. HELPFUL



In healthcare, words matter; the way we speak to patients can either build trust and dignity or reinforce harm and stigma. Sometimes, we say things with the best intentions, but those words may unintentionally carry bias, judgment, or assumptions that leave patients feeling dismissed, shamed, or unheard.

This handout offers common examples of “helpful vs. harmful” phrases to highlight how language can shift from unintentionally harmful to truly helpful, so that every patient experiences care that values their humanity.

One important concept to keep in mind is how unconscious biases about race, gender, and ability can lead us to undervalue patient experiences, police patient tone, or otherwise dismiss the reality of those seeking care. One way this can show up in care is by unknowingly reinforcing the [hierarchy of ableism and privilege.]

We are all conditioned to view disabilities through a deficit lens, meaning we will sometimes encourage patients to try and appear less disabled, or privilege those with disabilities that appear more aligned with able-bodied and neurotypical norms.

HARMFUL VS. HELPFUL

EXAMPLES

Photo by Chona Kasinger, Disabled and Here

HARMFUL	HELPFUL
"Type 2 is preventable; you could have avoided this."	*"Managing diabetes can be complex and looks different for each person. Let's make a plan together that works for you."*
Blames the patient and oversimplifies a complex condition that is informed by epigenetic factors like generational trauma and lifelong stress due to systemic racism & sexism.	Focuses on patient needs and supports empowerment without judgment.

continued →

HARMFUL →	HELPFUL
"You just need to try harder to be more active." OR *"You need to be exercising more often."* Assumes lack of patient motivation or effort and ignores barriers like pain, disability, or access.	*"Managing diabetes can be complex and looks different for each person. Let's make a plan together that works for you."* Individualizes care by asking what is realistic and respectful for the patient.

HARMFUL →	HELPFUL
"Don't worry, everyone feels anxious sometimes." Minimizes mental health concerns and discourages disclosure.	*"Thank you for sharing that with me. How does anxiety show up for you, and what support do you need?"* Acknowledges courage in sharing and explores patient-specific needs.

continued →

HARMFUL

“You don’t look disabled.” OR *“You look like you’re managing pretty well.”*

Invalidates nonapparent disabilities, makes assumptions, and/or suggests doubt.

HELPFUL

“Thank you for letting me know about your disability. Are there any accommodations you need to make today's appointment and your care plan more accessible for you?”

Trusts the patient’s disclosure and proactively offers support for access needs.

HARMFUL

“You should be grateful— it could be worse.”

Dismisses emotional response and pressures toxic positivity.

HELPFUL

“It’s okay to feel frustrated. Your experiences and feelings are valid.”

Validates feelings and makes space for authentic expression.

continued →

HARMFUL

"She's wheelchair-bound."

Suggests restriction or pity rather than access or mobility.

HELPFUL

"She uses a wheelchair."

Uses neutral, empowering language that reflects autonomy.

HARMFUL

"That's just part of getting older."

Normalizes suffering and discourages intervention.

HELPFUL

"Let's look at what might be causing that change & see what we can do to improve your quality of life."

Shows curiosity and commitment to maintaining well-being at every age.

HARMFUL

"You don't need to be rude, I've already told you everything you need to know."

Projecting based on racial or gendered identity, tone policing.

HELPFUL

"I understand wanting to understand everything thoroughly, it's a lot of information. What other questions did you have?"

Leads with empathy, validates the patient's experience.

REFLECTION QUESTIONS

Before responding to a patient, ask yourself:

1. AM I ASSUMING OR JUDGING?

- Does my statement place blame or create a hierarchy between patients?
- Does my statement imply ableist biases regarding quality of life?
- Am I tone policing or otherwise expecting certain behavior from my patient?

2. AM I CENTERING THE PATIENT'S EXPERIENCE?

- Does my statement place blame or create a hierarchy between patients?
- Does my statement imply ableist biases regarding quality of life?
- Am I tone policing or otherwise expecting certain behavior from my patient?

3. AM I VALIDATING AND EMPOWERING?

- Does my language acknowledge the patient's reality and offer support without minimizing or dismissing it?
- Am I managing my own feelings of frustration or defensiveness so patients can share their experiences honestly?
- Am I aware of my own biases around race, gender, culture, and more, and do I know how to mitigate my own biases and pitfalls?

★ *TIP: As you reflect, pause and reframe your words as needed to focus on collaboration, respect, and the patient's individual, lived experiences.*

Disability Justice in Public Health

VOCABULARY, RESOURCES, KEY POINTS

eLearning Companion Guide

UNIT 1

Vocabulary

Ableism

The unfair treatment, discrimination, and social prejudice against people with disabilities, based on the belief that being able-bodied and neurotypical is superior.

Neurodivergent

A person whose brain has differences from what is considered the norm that affect how they learn, process, understand, and remember things. This includes autism, ADHD, OCD, Trisomy 21 or Down Syndrome, and other neurological conditions.

Neurodiversity

A way of thinking about the variances of human minds, both those considered neurotypical and those considered neurodivergent, that recognizes there is no “normal” brain, since no two brains are exactly alike. A group of people where some are neurotypical and others are neurodivergent is neurodiverse.

Neurotypical

A person who has what is considered a “normal” or “average” brain, and whose neurocognitive functioning falls within expected ranges. A person who learns, processes, understands, and remembers things in ways that are supported by social systems and norms.

UNIT 1

Resources

TITLE & LINK	DESCRIPTION
National Institute of Health (NIH)	Research on the preferences for identity-first versus person-first language in a US sample of autism stakeholders.
Autistic Self Advocacy Network (ASAN)	Website to expand on Identity-First Language and other advocacy supports.
Social Model of Disability Video	Explore the Social Model of Disability by learning how the Social model differs from the traditional Medical model, and how we can define disability.
What is Ableism Video	Persons with disabilities are rights-holders and their rights must be respected, protected and fulfilled, just like everyone else. Video provides examples of ableism in our communities, and suggests ways we can change our approach.
Legos and the 4 I's of Oppression Video	This framework is adapted from the People's Institute for Survival and Beyond's Undoing Racism training. The video explores how ideological, interpersonal, institutional, and internalized oppressions impact people's lives.

UNIT 1

Key Points

1. **The Deficit Model of Disability** believes that people must adapt to their environment, while the **Social Model of Disability** believes that the environment must adapt to the needs of the people.

2. **We can reframe our Deficit Model framework** of disability to a more Social Model framework of disability, and this will push us to have higher standards around accessibility and inclusion in our healthcare environments.

3. **To address the ableism impacting our patients**, we must include personal reflection about our internalized beliefs, changing our interpersonal interactions, assessing the bias in our institutions and challenging widespread ideologies about ability and access in our approach.

4. **Everyone who is currently able-bodied or neurotypical benefits from systems that make value-based judgements** on those who are disabled and neurodivergent, and we must examine the internalized superiority and inferiority around ability this reinforces.

UNIT 2

Vocabulary

Bodyminds

Language from Disability Justice Movement leader Eli Clare that represents how our bodies and minds are connected and work together as one - they can't be separated.

Disability Justice

A framework developed by queer and trans disabled People of Color, building upon the disability rights movement by recognizing that people can face multiple challenges at once - not just because of disability, but also because of their race, gender, or other parts of who they are. Sins Invalid is a disabled artist collective that developed the Disability Justice Principles.

Person-Centered Care

An approach to healthcare that prioritizes the individual's preferences, values, goals, and lived experiences in all aspects of care planning and delivery. It involves actively listening to and partnering with the person receiving care, recognizing their expertise in their own body and needs, and ensuring care decisions reflect their unique identity and choices.

UNIT 2

Resources

TITLE & LINK	DESCRIPTION
Transition to Adulthood: A Health Care Guide for Youth and Families	Like all youth approaching adulthood, people with disabilities and their families need to plan for the future. This document can be shared with families and youth make sure young adults are prepared to make their own decisions.
Take Charge: A Reproductive Health Guide for Women with Disabilities	This guide offers suggestions to patients on how to self-advocate to exercise these rights and overcome barriers that could result in denial of care or in services that are unsafe or of poor quality.
RealTalk: Provider Toolkit Improving Quality of Sexual Health Care for Patients with Disabilities	Providing information on what providers need to know, questions to ask yourself, and questions to ask the patient.

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UNIT 2

Resources

TITLE & LINK	DESCRIPTION
Addressing Concerns and Attitudinal Barriers for Adults with I/DD	Guiding principles for hard conversation and possible responses to language you may hear people use.
Addressing Attitudinal Barriers to Disability Competent Care	The Centers for Medicare and Medicaid Services developed the Disability Competent Care Model to address inequities in healthcare for people with disabilities by promoting whole-person, participant-centered care that eliminates bias and respects individual choice.
How to Provide Culturally Competent Care for Patients with Disabilities	Tips on providing quality care to patients who have a disability.

UNIT 2

Key Points

1. **To ensure inclusive healthcare, we must proactively address both environmental barriers and ableist attitudes** that exist among clinical teams, administrators, caregivers, disability support people, and patients regarding accessible and comprehensive care delivery.

2. **Through evidence-based advocacy strategies and accurate information**, we work to ensure patients with disabilities receive equitable, accessible healthcare comparable to that provided to non-disabled individuals.

3. **Comprehensive healthcare**, including understanding of body, relationships, and safety, is a **fundamental right** that must be equally accessible to both disabled and non-disabled individuals with the same level of care, information, and support.

UNIT 3

Vocabulary

Eugenics

The practice whereby medical and legal institutions attempt to control the population based on perceived “desirable” traits and “undesirable” traits. Eugenicist practices have inflicted significant harm, especially on People of Color, disabled individuals, and LGBTQ+ individuals. This might look like deciding who is born, who is able to have kids, who is given healthcare, and who is allowed or encouraged to die, in order to create a specific “desirable” population.

Intersectionality

Recognizing and acknowledging that identity consists of multiple overlapping social categories, such as race, gender, class, or sexual orientation.

Structural Oppression

The rules, laws, and ways things are done in a society make life harder for some groups of people while giving more help or power to others. This unfair treatment keeps happening over time and causes even larger gaps for access.

UNIT 3

Resources

TITLE & LINK	DESCRIPTION
Eugenics and Scientific Racism	Eugenics is an inaccurate theory linked to historical and present-day forms of discrimination, racism, ableism and colonialism. It has persisted in policies and beliefs around the world, including the United States.
Eugenics and Disability	Resource hub for understanding the history and impact of eugenics on disabled people, especially those who are multi-marginalized.
Reproductive Justice is Disability Justice: Part 1 Video	Who has the right to make choices about their bodyminds and their healthcare? Which bodies are seen as worthy of bodily autonomy? These questions are both central to the Reproductive Justice and Disability Justice, two movements intertwined in their origins and organizing.
What is Reproductive Justice Video	Maternal health experts Dr. Monica R. McLemore and Dr. Karen Scott explain the four main tenants of reproductive justice.

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UNIT 3

Resources

TITLE & LINK	DESCRIPTION
My Body Doesn't Oppress Me, Society Does Video	Patty Berne and Stacey Milbern present a social model of disability, explaining how universal design, adaptive devices, and meeting people's access needs can limit the social, economic, and physical barriers that render physical impairments disabling in an ableist society.
Sins Invalid	Sins Invalid is a disability justice-based movement building and performance project that celebrates disabled people, centering and led by disabled Black, Indigenous, and people of the global majority, and queer, trans, and nonbinary disabled people.
Sins Invalid Movie Trailer	Sins Invalid is a performance project of artists with disabilities, centralizing artists of color and queer and gender-variant artists.
No Body is Disposable	The videos in the series "No Body Is Disposable" offer snapshots of this framework and tools for activists, educators, and students to bring to their communities.

UNIT 3

Key Points

1. **Advocating for inclusive healthcare for individuals with disabilities is essential**. This advocacy challenges the longstanding ableist and dehumanizing ideologies that have historically denied disabled people the same rights and bodily autonomy as their non-disabled peers.

2. **We must understand the intersectional experience** of folks with multiple marginalized identities, particularly disabled People of Color, and ensure we are providing appropriate and culturally responsive supports.

3. **The Disability Justice framework prioritizes equity for all and centers multiple marginalized experiences**, providing a more comprehensive approach than the initial aims of the disability rights movement.

UNIT 4

Vocabulary

Shared Decision-Making Model (SDM)

In a Shared Decision-Making Model a doctor or provider and the patient work together to explore various health care options and decide on the best course of treatment considering “what matters most” to the patient. (This is different than the Supported Decision-Making Model which also involves the use of a support person, chosen by the patient with I/DD to assist.)

UNIT 4

Resources

TITLE & LINK	DESCRIPTION
Disability Justice: An Audit Tool	"Disability Justice: An Audit Tool" is aimed at helping Black, Indigenous and POC-led organizations (that are not primarily focused around disability) examine where they're at in practicing disability justice, and where they want to learn and grow.
Plain Language Disability Justice Principles	This site offers a tool with plain language breakdown of the principles.
How to Provide Culturally Competent Care for Patients with Disabilities	This resource is designed to help healthcare providers deliver culturally competent, accessible, and patient-centered care to people with disabilities. The goal is to reduce barriers and health disparities by improving understanding, communication, and care practices for patients with a wide range of disabilities.

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UNIT 4

Resources

TITLE & LINK	DESCRIPTION
Plan Language Materials Development Checklist	The Plain Language Materials Development Checklist from Harvard Catalyst is a practical tool to help people who create written materials make sure their content is clear, accessible, and useful for their intended audience.
RealTalk: Provider Toolkit	A document aimed at improving the quality of sexual health care for patients with disabilities.
AAFP: About Shared Decision-Making Model	Learn more about shared decision-making at this site.
Partners in Health	Implementing Shared Healthcare Decision-Making for Users of Augmentative and Alternative Communication in California.
The Conversation Project	This site offers many conversation starter guides.
Addressing Ableism: Harmful Vs. Helpful	This handout addresses ableist comments in healthcare settings with examples, suggested rephrases and reflection questions.

UNIT 4

Key Points

1. **Disability Justice requires dismantling personal biases and oppressive clinical frameworks**. Clinicians must actively reflect on and reshape clinical spaces, systems, and practices to better serve disabled people, especially those at the intersections of multiple forms of oppression.

2. **Know your sphere of control**. Understanding what's within your power helps identify where you can meaningfully disrupt ableist systems and advocate for change. We must also understand how oppression operates on multiple levels, using tools like the 4Is to analyze impact and personal capacity.

3. **Support choice and consent**. Using Shared Decision-Making in clinical care promotes patient autonomy, dignity, and informed consent, especially for people with I/DD.

Introduction to the Training Package

The Training Package is designed to support organizations conducting internal training. It includes the **training outline, slide deck,** and **participant notecatcher** and is meant to accompany the eLearning and Self-Advocacy Tools.

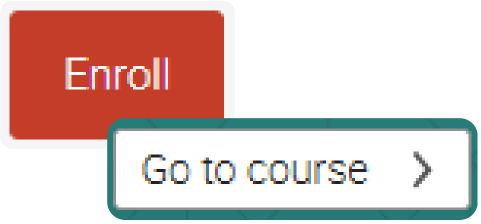
Note that the training requires personal reflection and facilitated discussion of the systemic barriers informed by racism, sexism, ableism and more, and require time and space to process and integrate the learning.

If you would like to contract Cardea Services to provide experienced facilitators and a tailored training experience, contact us at healtheducation@cardeaservices.org.

eLearning Access

This four-module eLearning course includes Understanding Ability and Access, Removing Barriers, Foundations of Disability Justice, and Disability Justice in the Healthcare Setting.

1. **NAVIGATE TO THE COURSE HERE.**
2. **LOG IN, OR CREATE A PROFILE** (IF NEW USER)
3. **CLICK THE RED "ENROLL" BUTTON**



4. **CLICK "GO TO COURSE"** (IN THE TOP RIGHT CORNER)
5. **TIME TO LEARN!**

Live Session Training Outline

An outline for a 2.5 hour live training session. This session builds on the eLearning course (previous page) and is designed so organizations can train their staff.

Navigate here to access the outline.

Live Session Slide Deck

Slide deck for the training including speaker notes for facilitators. Accompanies the Training Outline.

Cardea WITH

Disability Justice in Public Health

Centering Women of Color with I/DD

Month XX, 20XX

Navigate [here](#) to access the slide deck.

Participant Notecatcher

Notecatcher for training participants including reflection questions, reminders, and a content overview.

Disability Justice in Public Health

Centering

Training Note-Catcher

Navigate here to access the notecatcher.