Best Practices for Providing High-Quality Palliative Care for People with Disabilities

March 18, 2025

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National Seminar 2025

September 15-17, 2025 • Philadelphia, PA

capc.org/seminar

Faculty

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Webinar Goals

Awareness

- Consider disability.

Acceptance

- Learn about your bias and shift your perspective around disability.

Action

- Shift your practice and advocate **for** and include your **patients** with disabilities and their needs.

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What is Disability?

What is Disability?

Disability Impacts 1-Billion People Worldwide. Anyone can become disabled at any time.

"If you have a **physical** or **mental condition** that you must think about or plan around every day, then you have a disability." – Andrew Pulrang

The severity of an impairment doesn't always = the severity of disability.

Some people with serious illness or significant impairments do not use the word "disability" to describe their experience. Reasons for this include generational preference, stigma (internal and external), and cultural norms and values.

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Why do we say Disability?

- It's the word that gives us civil rights.
- It's unifying – speaks to common experience of ableism.
- It destigmatizes the presence of disability.
- It acknowledges that there are things that we cannot do, even with the best attitude.
- It makes us feel less alone.

Audience Polling

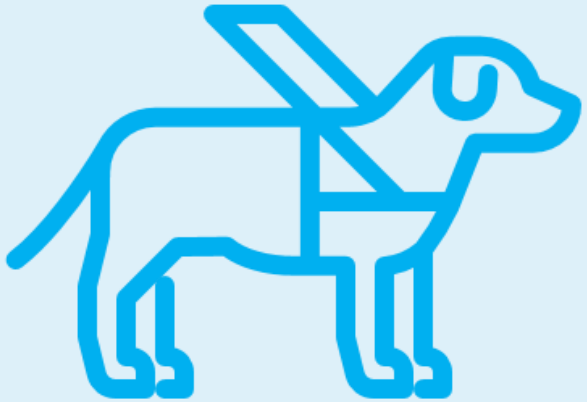
Have you had any training on disability in healthcare?

A. Formal education

B. Work-related training

C. Lived / personal experience

D. None



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History of disability

Institutionalization and Eugenics

- Sick
- Diseased
- Curable or incurable

Civil Rights

- Minority group that experiences discrimination
- Pushing towards visibility and a role in public life

1970s –

Freak shows

- Monstrous
- Freakish
- Exotic
- Villainous

Inspirational model

- Needing charity
- Childlike
- Helpless
- Objects of pity
- Inspirational – but only when acting non-disabled

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KATY PERRY @katyperry · 15h

welp. I just updated my font size on my phone #thisis40

Hector Minto
@hminto

Welcome to the amazing world of #accessibility.

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Disability Health Disparities

Health Disparities

People with disabilities face worse health outcomes and greater barriers to care than their nondisabled peers (NIMHD):

- Higher prevalence of certain diseases
- Increased morbidity, mortality, and health risk factors
- Lower rates of preventive care
- Physical and access barriers to quality healthcare
- Lower care satisfaction, impacted by stigma, bias, and ableism

NIH formally recognized disability as a disparity population in September 2023.

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Clinician Perception

The New York Times

These Doctors Admit They Don't Want Patients With Disabilities

When granted anonymity in focus groups, physicians let their guards down and shared opinions consistent with experiences of many people with disabilities.

Share full article 1.2K

Lisa Iezzoni, a professor of medicine at Harvard, wanted to understand why people with disabilities kept reporting receiving substandard care. "I thought I needed to start talking to doctors," she said. M. Scott Brauer for The New York Times

Harvard Surveys 714 Physicians (2021)

Only **2/5** were very confident about their ability to provide care to patients with disabilities.

68% were concerned that they are at risk for an ADA lawsuit.

82.4% believe that people with a significant disability have worse quality of life than nondisabled people.

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Source: Physicians' Perceptions Of People With Disability And Their Health Care, Health Affairs, 2021.

Chat Question

Think about where you practice:

What barriers have you seen that impact the healthcare experiences of people with disabilities?

Infrastructure

- **Exam tables** and chairs may not be adjustable
- **Scales** may fail to accommodate wheelchairs or require a step-up
- **Patient portals** may be inaccessible to people with visual disabilities or intellectual/developmental disabilities
- **Braille or plain language** may not be available in printed materials
- **Sign language** interpreters, amplification devices, and whiteboards may not be available

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What can providers do?

Chat Question

Let's start at the foundation:

What does the word Ableism mean to you?

Ableism

"Ableism is the discrimination of and social prejudice against people with disabilities based on the belief that typical abilities are superior."

At its heart, ableism is rooted in the assumption that disabled people require **‘fixing’** and defines people by their disability. Like racism and sexism, ableism classifies entire groups of people as ‘**less than**’, and includes harmful stereotypes, misconceptions, and generalizations of people with disabilities.

- Access Living

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What can providers do on an individual level?

- **Recognize your relationship with disability**
  - Acknowledge how you relate to disability and any discomfort that may arise
- **Shift perspective**
  - Focus on changing attitudes toward disability, not changing the person who has the disability
- **Avoid assumptions & foster open conversations**
  - Welcoming discussions about disability and accommodations promotes collaboration
  - Asking about needs and understand that sometimes people may not be ready or comfortable sharing their needs
  - In situations where individuals may be unsure or unable to voice their needs, advocacy becomes crucial

What can providers do on an individual level?

Interpersonal Skills

- Consider approaching disability from a position of neutrality
- Unless explicit permission is provided, assistive technology is off-limits to touching – it is an extension of someone's personhood. This includes wheelchairs, hearing aids, canes, prosthesis, guide dogs, etc.
- When speaking with someone who uses a wheelchair, match your eye-gaze by positioning yourself to the physical level of the person

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What can providers do on an individual level?

Language etiquette

- **Use the language that the person is using**
  - *Person first can be preferred; some people use disability first.*
- **When creating public-facing documents, use “disability”**
- **Avoid any form of communication that is infantilizing.**
  - *Especially true when patient has I/DD.*

What can providers do on an individual level?

Promote self-expression

- If a patient is non-speaking, explore their methods for self-expression and create opportunities for engaging.
- Allow extra time for people who have communication, processing, or other related disabilities – it promotes the opportunity to fully express oneself
- If you're ever unsure, take the time to clarify rather than pretend to understand

What can providers do on a systemic level?

- **Advocate** for data collection on the EHR; be mindful of using patient-centered language when documenting (E.g., a person who uses a wheelchair)
- **Advocate** for accessible medical and diagnostic equipment (MDE) – leverage new regulations if needed
- **Leverage and support** your employee resource groups
- **Elevate** accessibility in your organization – advocate for sufficient resource allocation. Disability is intersectional and belongs in all conversations surrounding health equity.
- **Ensure** disability representation in leadership
- **Integrate** or establish disability in your PFAC structure

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Clinical Example

Imagine you will be working with a person who has cerebral palsy and a mild intellectual disability. They have requested palliative care while undergoing curative cancer treatment. They are a strong self-advocate.

The patient felt positively about their quality of life prior to cancer. They had a consistent weekly routine including part-time work in the community, engaging with friends and family, and social/leisure activities. The patient wants symptom relief (reduced pain, increased energy).

What are you thinking about as you learn about this prospective patient?

What may the barriers and/or supports be as they begin receiving palliative care?

Clinical Example

Imagine you are providing coverage to a person who is autistic (no intellectual disability). The individual has a close relationship with their primary palliative care provider, who is currently away.

You receive a call that the patient is experiencing an increase in their daily pain as well as difficulty sleeping.

What is your first step?

What do you want to know more about?

Communication and Trauma Informed Care Approach

There Are Unique Considerations in Advance Care Planning (Goals of Care)

A Trauma-Informed Approach Can Facilitate Engagement With Palliative Care

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Full article: https://www.capc.org/blog/top-ten-tips-palliative-care-clinicians-should-know-about-providing-care-for-people-with-disabilities/

Where can you get more info?

- Johns Hopkins: Johns Hopkins University Disability Health Research Center
- Docs with disabilities: Docs With Disabilities
- Home - Disability Equity Collaborative
- Healthcare Access Archives – DREDF
- Institute for Exceptional Care
- End Of Life Care Planning | The Victoria And Stuart Project

Join April Office Hour with Sarah!

VIRTUAL OFFICE HOURS

Achieving Health Equity and Reducing Implicit Bias in Palliative Care

WHEN

Monday, March 24
noon - 1 p.m. ET
REGISTER

Friday, April 25
2 p.m. - 3 p.m. ET
REGISTER

Monday, May 5
2 p.m. - 3 p.m. ET
REGISTER

Monday, June 9
noon - 1 p.m. ET
REGISTER

Join us for this small-group consulting call to ask questions and discuss health disparities that exist in the care of people living with serious illness—specifically, palliative care. This includes talking through effective strategies to increase self-awareness in contributing to implicit bias, normalizing difficult conversations with team members, and sharing ways to create a culture of transparency and accountability within our organization(s).

This Virtual Office Hours session will be hosted by Brittany Chambers, CAPC's Director of Health Equity, and an additional faculty member. See below for the schedule:

March: Karen Bullock

April: Sarah Quinto

May: Jeanna Ford

June: Brittany Chambers and Rayna Ross

These sessions are free and open to all.

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Join us on the CAPC Circles platform to connect and engage with palliative care and serious illness leaders dedicated to advancing health equity! This is a space where you can share resources, ask questions, and participate in meaningful discussions anytime. We look forward to your contributions and can’t wait to foster a vibrant community together!

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Q&A