

Special Bulletin #3

Healthcare Rationing: Helping People with Disabilities to be Seen as PEOPLE, First

Decisions like who gets an intensive care bed, an organ transplant, or a cancer screening are being made by healthcare providers every day. In this time of the COVID-19 pandemic, we must ensure that people with IDD are seen as people first. While the reasons for healthcare decisions are multifactorial, helping healthcare providers and the population at large see the human side of people with IDD can help level the playing field.

Laws and Policy

The Americans with Disabilities Act (ADA) and Section 504 of the Rehabilitation Act require that health care providers provide individuals with disabilities full and equal access to health care services and facilities. Out of concern for recent guidance regarding lower prioritization of critical care and ventilator access to people with disabilities, states have recently been reminded by the Office of Civil Rights that “persons with disabilities should not be denied medical care based on stereotypes, assessments of the quality of life, or judgments about a person’s relative ‘worth’ based on the presence or absence of disabilities.”

In an April 2020 policy statement regarding ventilators and COVID-19, The American Academy of Developmental Medicine and Dentistry resolved “that the presence of an intellectual or developmental disability must not be used as an exclusion criterion for ventilator support or the allocation of other scarce medical resources.”

What Can Each of Us Do



While there are laws and policies which are intended to prevent discrimination, they are not always followed. But there are also things that each of us can do on a daily basis to help others see the human side of people we support. Here's what we can do:

In conversations with healthcare providers and others:

- ▶ Lead off with who the person is rather than their diagnoses
- ▶ Introduce them to others with respect and importance
- ▶ Describe their quality of life positively
- ▶ Ask about screening during healthcare visits
- ▶ Speak TO the person and encourage others to do the same during healthcare visits

Establishing a positive relationship with other staff in an office is very helpful, as well. Let's look at some examples of each of these suggestions:

Leading Off With Who the Person is Rather Than Their Diagnoses

It's important to establish the person's positive personality as early as possible. A good introduction statement at a healthcare visit might look like this:

"This is Mike, he's an avid watcher of sports. In fact, you should see him cheer when someone hits a home run! His favorite team is the Cubs, but lately his vision seems to be keeping him from seeing the games well."

In this brief statement, Mike is identified as a sports fan, a person who has likes and dislikes just like everyone else and someone who reacts with emotional responses to different circumstances. Then, it identifies what the problem is and why it's important to resolve it.

Introduce Them to Others With Respect and Importance

"This is John. He's the opinion leader in our home."

Wow, the "opinion leader"! The person who others listen to with respect and authority - he is an important person among his friends and housemates. And, it's important that we address his health concerns, too.

Describe Their Quality of Life Positively

"When Susan goes to church, she's having a harder time going up the steps. Her friend who is the usher is having to provide more assistance and was asking what's going on." Susan participates in community life, and she has friends in the community that are concerned about her.

Ask About Screening During Healthcare Visits

Health disparities exist, and one of them is that people with IDD are less likely to have had screenings for cancer and preventive care. Asking about them can help remind healthcare providers to do these.

"Is it about time for her mammogram?" "At what age do you recommend that his cholesterol should be checked?"

Speak TO The Person and Encourage Others to Do the Same During Healthcare Visits

Conversations during healthcare visits are often mainly between the support person accompanying the person with IDD to the visit and the healthcare provider. Simple

statements can gently direct the conversation in a better direction.

“That’s a good question, let’s ask Jack.” “I don’t know doc, let’s see what Mary thinks about your recommendation.”

If the practitioner persists in talking to you rather than the person, you can often redirect by asking the person yourself. “Julie, would you point to where you are hurting?”

When You Can’t Be There – The Health Passport

When you or someone who knows the person best can’t attend and advocate for someone at a healthcare visit, there is a document that can help. It’s called a Health Passport. A Health Passport is a document that provides concise demographic and medical information about a person, but most importantly, information about the person themselves including things like:

- ▶ How I indicate that I’m in pain
- ▶ What my likes and dislikes are
- ▶ How I show joy, anger, etc.
- ▶ What helps me to remain calm
- ▶ What’s the best way to communicate with me?
- ▶ And much more


There are a number of versions of Health Passports around, and you may already be using one of your own. If you need one, you can freely download the HRST My Health Passport at HRSTonline.com. If you are utilizing the HRST, it’s a feature that’s built into each person’s record.

Send a Health Passport with someone when they go to a hospital or clinical visit, or if they are in a situation where there may be supporters who are unfamiliar with them as it can provide invaluable health and support information to others.

Call to Action

You’ve seen that there are actions that each of us can do on a daily basis to help people with disabilities to be recognized as valuable, important, and equal to everyone else. Implement these techniques into your daily routines when supporting them and teach others to do the same.

Click the button below to learn more about what we’ve discussed here by watching the recorded webinar titled **Disparities, Perceptions, and Misconceptions: Putting PEOPLE Before their Diagnoses**.



**Disparities, Perceptions
and Misconceptions:
Putting PEOPLE Before
Their Diagnoses**



**▶ WATCH
RECORDING**

Thank you for all that you do, every day in supporting people with disabilities to live healthier and more fulfilling lives.

CLICK HERE

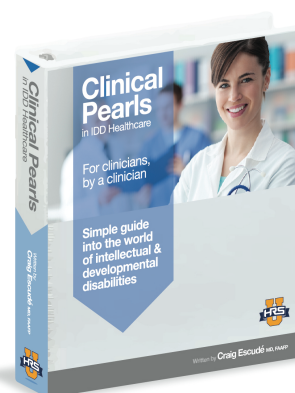
**The latest info on how
to support others during
the COVID-19 pandemic**

Clinical Pearls in IDD Healthcare

A “Clinical Pearl” is a small bit of helpful clinical information based on experience or observation.

Clinicians get little to no training for the care of people with IDD. Help them be as effective as possible by handing them one of the 50+ Pearls during the next appointment.

**Nothing like it available
anywhere!**



**Person-centered guide
into the world of IDD**



▶ LEARN MORE