Do You Really See Me?

An ACPE Academy Webinar Series

An Introduction to Understanding the Models of Disability and Terminology
Presenters

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Meggie Kobb, Staff Chaplain at the Hospital of the University of Pennsylvania who covers the Emergency Department, ED Observation Unit, and the Psychiatric Emergency Evaluation Center. She did a CPE residency at Penn, and, as the proud mother of a ten year old son on the autism spectrum, has used both her training and experience as chaplain with people with intellectual and developmental disabilities.

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Why this series?

• New national working group on Healthcare Decision Making formed by the Association of University Centers on Disabilities in response to experiences of people with intellectual and developmental disabilities and their families in acute care hospitals around the country.

• We are part of that working group, along with Trace Haythorn representing ACPE.

• Personal experiences as chaplains and as a parent.
  • The story of Brian, and encountering patients with IDDs in all areas of the hospital
What are we talking about?

Legal definition of disability:

“The ADA defines a person with a disability as a person who has a physical or mental impairment that substantially limits one or more major life activity. This includes people who have a record of such an impairment, even if they do not currently have a disability. It also includes individuals who do not have a disability but are regarded as having a disability.”

https://adata.org/faq/what-definition-disability-under-ada
Intellectual and Developmental Disabilities

• Intellectual disability is a disability characterized by significant limitations both in **intellectual functioning** (reasoning, learning, problem solving) and in **adaptive behavior**, which covers a range of everyday social and practical skills. This disability originates before the age of 18.

https://aaidd.org/intellectual-disability/definition#.VuBCC8fnvNU

• No longer an IQ measurement. All three parts of the definition apply

• Includes: what used to be called “mental retardation,” cerebral palsy, autism, fragile X, spina bifida, and others.
What do I call you?

• By name, preferably.

• Remember the power of naming.

• What label to use if talking about someone?

• Respectful choices can include “developmentally disabled,” “intellectual disability,” or “IDD”
Two national movements

• Ban the “R” word, part of ongoing efforts to use person centered language

• Just say the word. “Disabled.” Identity-centered.
  e.g. “the deaf,” I am “autistic.”
What is “normal?”

Mom? What is...Normal?

It’s just a setting on the dryer, honey.
What is “normal?”

There was no such concept until birth of mathematical averaging and statistical norms in the 19th century. As “the average” became a “norm,” and a factor contributing to fear of difference, and the eugenics movement.
What is autism?

Autism is a neurological disorder characterized by deficits in both language and communication.
Autism Spectrum Disorder

- Classic Autism
- High-Functioning Autism
- Asperger’s Disorder
- Atypical Asperger’s
- PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified)
- Childhood Disintegrative Disorder
- Sensory Processing Disorder
- Rett’s Disorder
DSM-5: Autism Spectrum Disorder

- Persistent deficits in social communication and social interaction
- Restricted, repetitive patterns of behavior, interests, or activities
- Symptoms are present in early childhood
- Symptoms limit or impair everyday functioning or relationships

(Tierney, 2015)
Common Behaviors in ASD

• Decreased eye contact
• Uneven development of skills
• Resistance to changes in routine
• Marked hyperactivity and/or extreme passivity, which may alternate
• Less demonstration of typical signs of affection
• Odd body movements or postures (flapping, spinning, etc.)

(Challman, 2015)
So what does that look like?

- Looking down, instead of at you when you speak
- Not answering questions, or not answering right away
- Not wanting to be touched
- Repetitive rocking, swaying or bouncing
- Walking only on toes
- Flapping hands
- Making noises that are not words
Sensory Sensitive

- Frequently, people on the Autism Spectrum experience sensory input more acutely.
- Increased sensitivity to heat/cold, light/dark, textures on clothing or surfaces, sound—especially loud noises, textures in foods, strong smells
- Easily overwhelmed or distracted
A growing population

• CDC: 1 in 68 children will be diagnosed with autism
• Recent government survey has even higher numbers...1 in 45.
• 2% of the population
Definition is an ever moving construct

- Disability originated as way of assessing which veterans should get public assistance.
- Rise of medical model with rise of medicine.
- Old diagnoses become pejorative labels: moron, feebleminded, imbecile
- Good facility based programs turned into institutions
- Eugenics furthered institutions as “the” solution.
- After WW II: Veterans, parents and conscientious objectors began the advocacy for change.
WHO 1980 Medical Model

- "International Classification of Impairments, Disabilities and Handicaps". The framework they proposed approached disability using the terms Impairment, Handicap and Disability.

- Impairment = a loss or abnormality of physical bodily structure or function, of logic-psychic origin, or physiological or anatomical origin

- Disability = any limitation or function loss deriving from impairment that prevents the performance of an activity in the time-lapse considered normal for a human being

- Handicap = the disadvantaged condition deriving from impairment or disability limiting a person performing a role considered normal in respect of their age, sex and social and cultural factors
Figure 1: ICIDH MODEL (WHO 1980)

Disease → impairment → Disability → Handicap

Disease or Disorder → Impairment (functional loss) → Disability (activity limitations) → Handicap (social disadvantage)

{organ level} → {person level} → {societal level}
Medical model to social model

The **social model of disability** is a reaction to the dominant **medical model of disability** which in itself is a functional analysis of the body as machine to be fixed in order to conform with normative values.\footnote{1} The social model of disability identifies systemic barriers, negative attitudes and exclusion by society (purposely or inadvertently) that mean society is the main contributory factor in disabling people. While **physical**, sensory, intellectual, or **psychological** variations may cause individual functional limitation or impairments, these do not have to lead to **disability** unless society fails to take account of and include people regardless of their individual differences. The origins of the approach can be traced to the 1960s; the specific term emerged from the **United Kingdom** in the 1980s.
Current WHO Model: 2001

- Health condition (disorder or disease)
- Body Functions & Structure
- Activity
- Participation
- Environmental Factors
- Personal Factors
- Contextual factors
Progression of responses

From fear...
to pity ...
to anger...
to love.
(Fr. John Aurelio, former chaplain, Buffalo area)

Comparable to historical stages of services and movements
From demonic/exclusion to ...
special services to...
civil rights to...
contribution and belonging
Your response as chaplain and pastor

- Shaped by your personal history
- Social and public constructions
- Frequent lack of exploration in seminary or CPE.
- Theological constructions
Language Guidelines

• Avoid the word “normal”; implies correctness or preference; introduce term “neuro-typical” instead
• Avoid euphemisms
• Avoid specialness and “inspiration porn”
• Ask individual and family—grants choice & respects autonomy
• Use personal name. Invite others to do same.
• Talk to person rather than caregiver. “Nothing about me without me!”
Potential encounters

• Birth and/or diagnosis
• Accident/trauma—the emergency department experience
• Can be sick just like anyone else.
• Disability ≠ Disease
• End of life
Patient Experiences

The Trauma Bay
Patient Experiences

- OVERWHELMING!
- Strangers all around
- They’re touching
- They’re talking
- Bright lights
- Siren outside
- So many needles
Patient Experiences

• Change in routine
• Different bed
• Different food
• Unfamiliar noises
• And all of this while you’re not feeling well
• Unsettled & anxious
Experiences of family

“Autism affects the entire family. A diagnosis of autism for one family member will affect the whole family system.”

(Walsh, 2008)
Unrelenting stress

- Caregiver stress that lasts a lifetime
- Nearly ½ of those diagnosed wander, leading to safety worries.
- 84% of adults with autism live with their parents.

(Autism Speaks)
• Mothers of adolescents and adults with autism experience chronic stress comparable to combat soldiers and struggle with frequent fatigue and work interruptions. These moms also spend significantly more time caregiving than moms of those without disabilities.

(Seltzer, 2009)
Fierce advocates

- Adversity & resilience
- Frequent exposure to medical professionals
- Years of experience advocating for their child
- Weary & wary
“And I would call, and they’d say, ‘We don’t treat autism.’ And I’d say, ‘I don’t want you to treat autism. I want you to treat my son.’”

--Suzanne Joseph, about her adult son
Needs unmet

• “Nurses and clergy cannot assume that membership in a faith community automatically brings social support or spiritual well-being.” (Speraw, 2006)
• Experiences of isolation
• Social stigmas surrounding autism
Duality of experience

• On the one hand, believing that their child is capable of relationship with a higher power.

• And yet experiencing isolation & social stigmatization that makes membership in a religious community fraught with difficulty.
Possibility of multiple hospitalizations

Chronic health/disability...hospital fatigue/trauma

• Who’s there? Family? Caregiving staff?
• What is their response?
• Do the caregivers draw closer, or is burnout part of their experience?
• Can be both.
• End of life. Presence and dignity
Complicating issues

- Disability overshadow the rest of their identity.
  - Healthcare passport
    [http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf)
- Intersectionality with so many other issues: culture, race, class, marginalization—disparities in care...age of diagnosis, availability of services, and even visibility in the disabled community; wide gulf between the experiences of white children & adults and minority children & adults
- Quality of life assumptions, can’t be fixed, negative prognosis.
- Consent, making decisions, voice in care
- Advocates lacking. Little training for physicians, no specialty.
- Challenge to the acute care culture: Intellect and pace, smart and fast, messes up the “normal” systems and boxes, productivity.
Public policy values that drive services

• Independence
• Productivity
• Inclusion
• Self Determination
• Cultural Competence

Spiritual issues at the heart of those values

- Independence: Who am I?
- Productivity: Why am I?
- Inclusion: Whose am I?
- Self determination: What power do I have? Voice and agency?
- Cultural competence: Will I be respected for my uniqueness and “differences?”
- Psalm 139 from Judeo-Christian perspective... “fearfully & wonderfully made”...can a person still be fearfully & wonderfully made if they are living with an IDD?
Theological issues

- Why the disability?
- Whose fault?
- Faith, healing, and cure
- Equation of faith with reason and intellect—
  Example: *Becky’s limited functional communication & vibrant prayer life*
- Spiritual history and stories: too often abuse and neglect
Pastoral responses

• Hear the stories
• Model radical acceptance & inclusivity
• Find other parts of identity and share them (i.e., see the strengths and interests)
• Listen to behavior
• Talk to those who know the person best
• Symbol and ritual can be crucial
• Simple but not childish
• Use core values of patient and family centered care
Questions?

Questions for the next two sessions:

If you have questions or topics you want to make sure we address, email:

- Bill Gaventa  bill.gaventa@gmail.com
- Meggie Kobb  KobbM@uphs.upenn.edu

Vignettes and/or verbatims: If you have some that have been excellent learning and teaching experiences, we’d love to get them for a resource pool that could be used by others. Make sure people and places are not identifiable.
Resources

**Web-based**

- *Advancing Effective Communication, Cultural Competence, and Patient- and Family- Centered Care: A Roadmap for Hospitals* [http://www.jointcommission.org/assets/1/6/aroadmapforhospitalsfinalversion727.pdf](http://www.jointcommission.org/assets/1/6/aroadmapforhospitalsfinalversion727.pdf)

- Language and terminology
  [https://www.disabilityisnatural.com/home.html](https://www.disabilityisnatural.com/home.html)

- *Portrayal of People with Disabilities.*
  [http://www.aucd.org/template/page.cfm?id=605](http://www.aucd.org/template/page.cfm?id=605)

Video

- **Video:**
  - A Credo for Support: (Five minutes. Powerful short history of disability and current requests for effective supports)
  - People First Version: [https://www.youtube.com/watch?v=wunHDfZFxXw](https://www.youtube.com/watch?v=wunHDfZFxXw)
  - Without narration: [https://www.youtube.com/watch?v=21uHYEqKOOw](https://www.youtube.com/watch?v=21uHYEqKOOw)

- **Ten Commandments for Communicating with People with Disabilities.** 25 minute videotape, perhaps available at local universities, libraries, or disability agencies. Excellent. Uses humor to illustrate ten common issues in communication with people with a variety of disabilities.
Variety of resources and published articles on the website:

http://faithanddisability.org/

Including information on the 2016 Summer Institute.


http://faithanddisability.org/projects/summer-institute/

Other resources to come with the 2nd and 3rd webinars
And better yet:

Invite some people with disabilities and/or their families and caregivers to come and share their hospital experiences with your program, congregation, etc.

Also a resource in every state:

• Parent to Parent networks: http://www.p2pusa.org/p2pusa/sitepages/p2p-home.aspx

• University Centers of Excellence in Developmental Disabilities
  Find the one or two in your state through www.aucd.org and learn about training and education opportunities they sponsor and/or coordinate.