

Spectrum of Care:

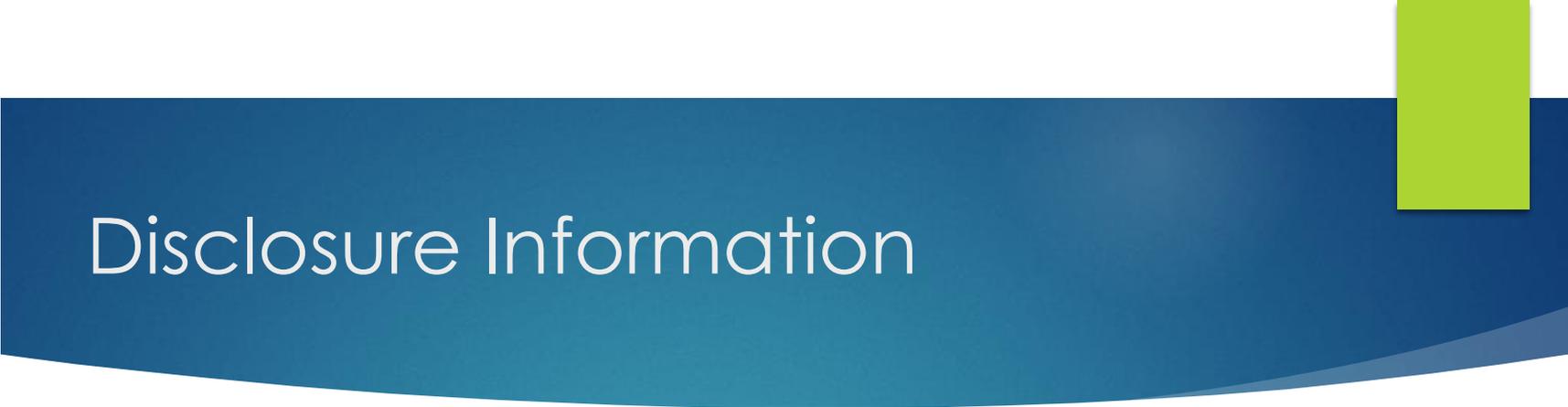
Engaging in chaplaincy with
individuals who have autism



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Disclosure Information

In the past 12 months, I have had no relevant financial relationships with the manufacturers of any commercial products and/or providers of commercial services discussed in this presentation.

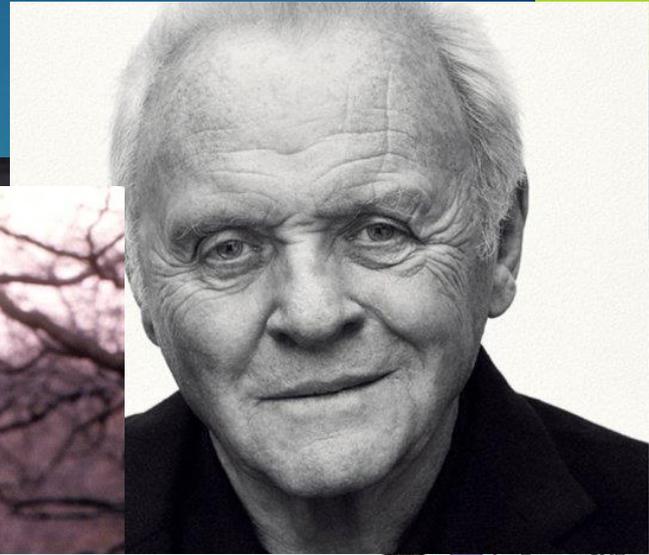
Objectives

- 1) Define Autism Spectrum Disorder, and explore the patient experience for that population and their caregivers.
- 2) Examine the shifting theology of disability.
- 3) Learn practical strategies of how to compassionately and competently engage with patients with ASD.

What is
autism?



Autism in the world

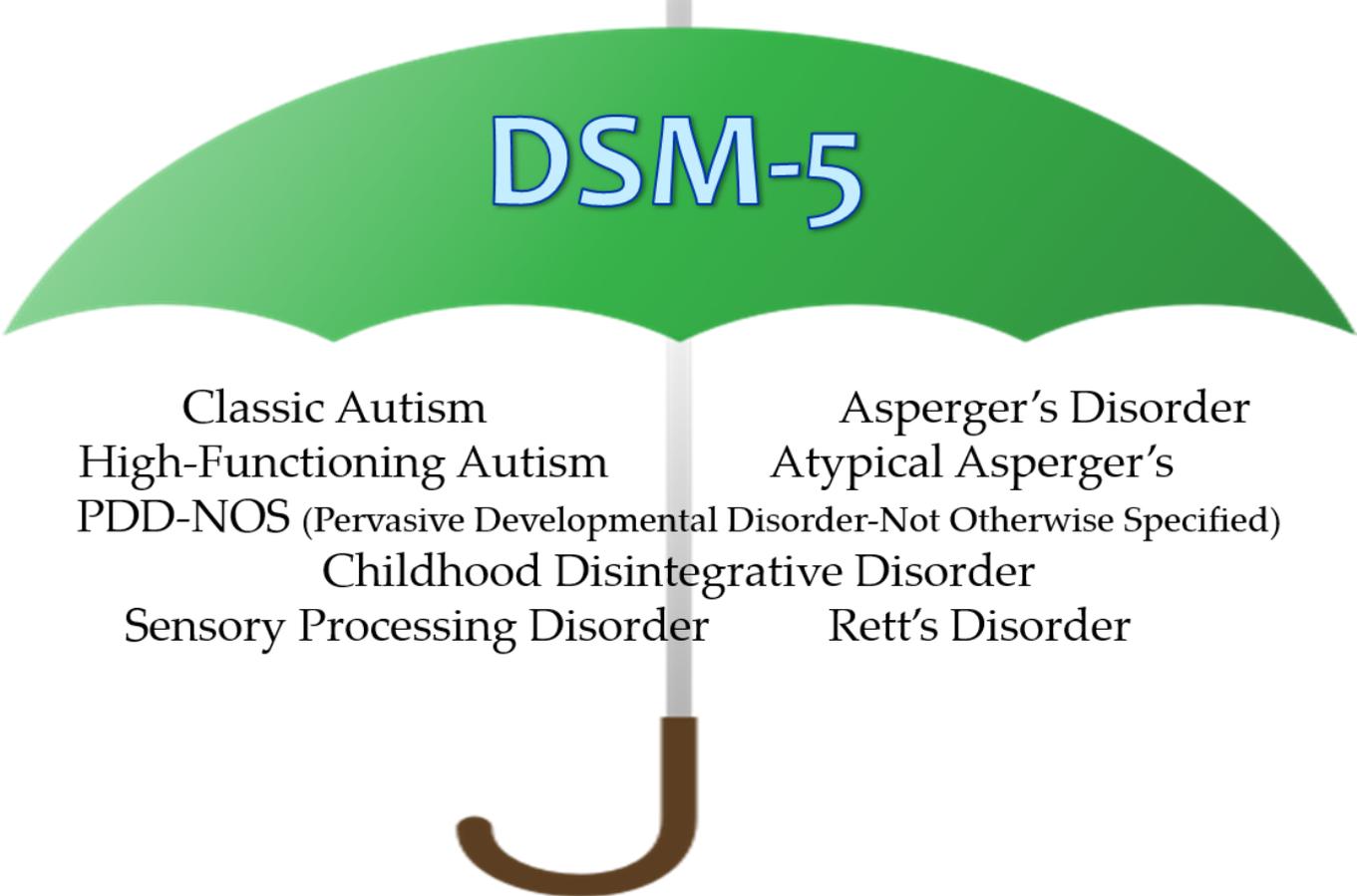




What is autism?

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

Autism Spectrum Disorder



DSM-5

Classic Autism
High-Functioning Autism
PDD-NOS (Pervasive Developmental Disorder-Not Otherwise Specified)
Childhood Disintegrative Disorder
Sensory Processing Disorder

Asperger's Disorder
Atypical Asperger's
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
- ▶ Stimming...repetitive rocking, swaying, bouncing or flapping hands
- ▶ Walking only on toes
- ▶ Vocalizations...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

Sensory Overload

▶ <https://vimeo.com/103896616>

Causes of Autism

**VACCINES
DO NOT
CAUSE AUTISM.**

The persistent vaccine myth

- ▶ Dr. Andrew Wakefield published a paper in 1998 falsely claiming that the MMR vaccine had caused autism in the children in his study.
- ▶ Sample size = 12
- ▶ Never replicated
- ▶ Falsified data
- ▶ Soundly rebuked by the medical community
- ▶ And yet the damage was done.

So then what does?

Genetic

- ▶ Gene deletion or mutation
- ▶ About a dozen genes where deletion is involved
- ▶ About two dozen genes where mutation is involved

Environmental

- ▶ All environmental influences happen *in utero*:
- ▶ Certain maternal infections
- ▶ Certain toxic exposures (often alcohol)
- ▶ Risk elevated with prematurity & parent age

A growing population

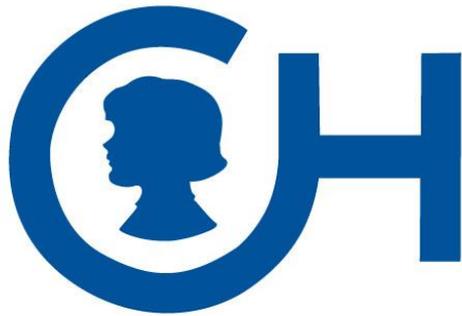
- ▶ CDC: 1 in 68 children will be diagnosed with autism
- ▶ Recent government survey has even higher numbers...1 in 45.
- ▶ 2% of the population = 6.5 million people in the US



The Philly Pipeline

From CHOP...

...to HUP



The Children's Hospital
of Philadelphia[®]



Penn Medicine

We need to be prepared for this ever-growing population.

Vocabulary for the spectrum



Our words matter!

- ▶ Person-centered language:
 - ▶ “patient with autism”
 - ▶ not “autistic patient”
 - ▶ If the patient is verbal, ask them their preference. Otherwise, default to person-centered.

- ▶ “On the spectrum”

“Normal”



- ▶ “Normal” implies that there is an “abnormal.”
 - ▶ Better choice:
neuro-typical
- ▶ Never use “retarded.”
 - ▶ Better choice:
developmentally disabled



Experiences of patients on the autism spectrum

Patient Experiences



Patient Experiences

- ▶ OVERWHELMING!
- ▶ Strangers all around
- ▶ They're touching
- ▶ They're talking
- ▶ Bright lights
- ▶ Siren outside
- ▶ So many needles



Patient Experiences



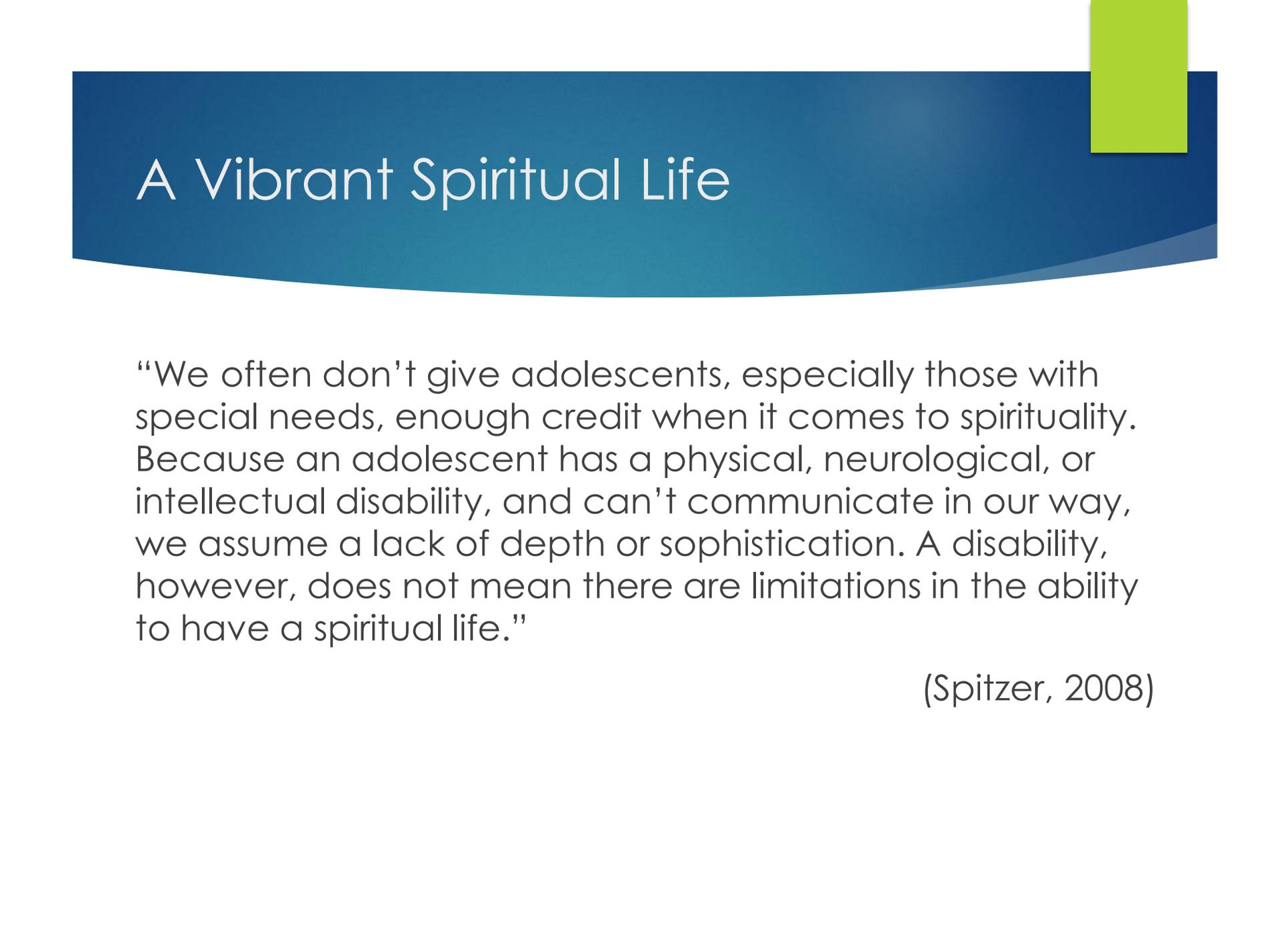
- ▶ Change in routine
- ▶ Different bed
- ▶ Different food
- ▶ Unfamiliar noises
- ▶ And all of this while you're not feeling well
- ▶ Unsettled & anxious

The challenge of non-verbal patients

- ▶ 1/3 of children and adults with autism are non-verbal.

(Autism Speaks)

- ▶ *How do you know if your patient is in pain?*
- ▶ *How do you know if your patient wants to visit?*
- ▶ *How do you engage in spiritual care with someone with social and language impairments?*



A Vibrant Spiritual Life

“We often don’t give adolescents, especially those with special needs, enough credit when it comes to spirituality. Because an adolescent has a physical, neurological, or intellectual disability, and can’t communicate in our way, we assume a lack of depth or sophistication. A disability, however, does not mean there are limitations in the ability to have a spiritual life.”

(Spitzer, 2008)

“Amelia” and her prayer life





Experiences of family & caregivers

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.
(CDC)
- ▶ 84% of adults with autism live with their parents.
(Autism Speaks)
- ▶ National shortage of specialized adult housing

Autism mom vs. soldier

- ▶ 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



Mom/Advocate

“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 David

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.

Your resident expert

- ▶ **You** are the expert in **chaplaincy**.
- ▶ The **caregiver** is the expert on **their loved one**.
 - ▶ They will be able to tell you:
 - ▶ What makes their loved one panic
 - ▶ How much sensory input will be too much
 - ▶ What name they prefer to be called
 - ▶ Which de-escalation techniques work best

Theology of Disability



Psalm 139:13-14

“For you created my inmost being;
you knit me together in my mother’s womb.

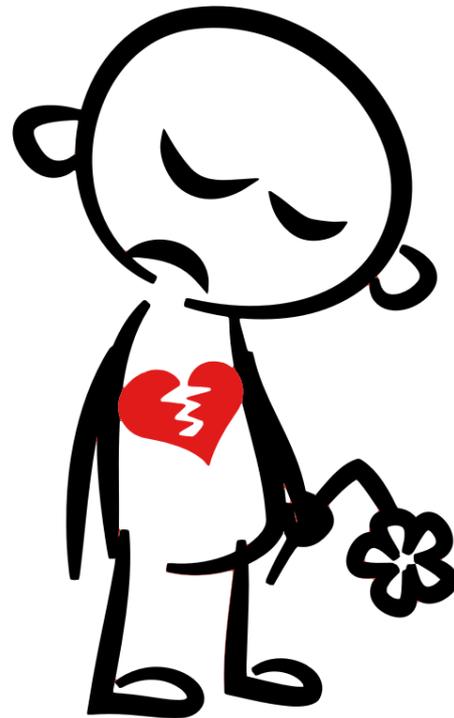
I praise you because I am fearfully and
wonderfully made;
your works are wonderful,
I know that full well.”

Theology of disability

- ▶ Can we still be “fearfully and wonderfully made” if we are disabled?

Broken people

- ▶ Old way of thinking: those with disabilities were somehow broken
- ▶ Frequently placed blame on the parents
- ▶ Viewed disabled people as “less-than”



An important shift

“My call for defining faith as a gift from God rather than a set of beliefs or a well-developed cognitive understanding of all things spiritual is, then, an attempt to encourage us to take seriously this tension from the ‘grace’ side of the equation so that children are recognized as fully [spiritual] beings from birth. If we hold this definition of faith as an act of grace, then we make room for children to be actual people of faith rather than just potential people of faith in need of further development before they can truly engage in a spiritual life...”

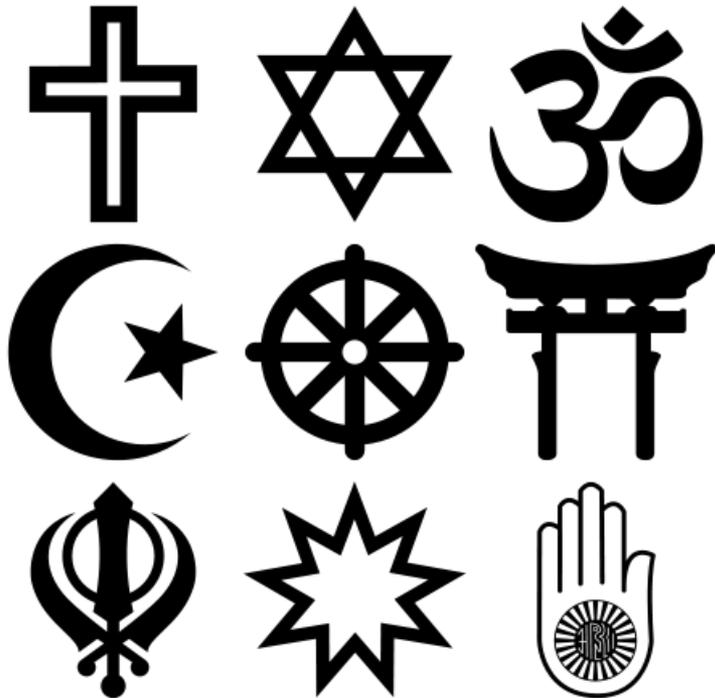


An important shift

“...If faith is not something we do but something we are given by God, then anyone can be a recipient of faith and respond with faithfulness, even if that person is incapable of rational reasoning.”

(Yust, qtd. in Conner 2010)

Changes across denominations



- Mormon perspective: Individuals with disabilities “are entitled to all the blessings that God has in store for His faithful and obedient children.” (Nelson, 1998)

Changes across denominations

- ▶ Pope Francis has spoken out several times in recent years about the need for inclusion
- ▶ Met with children on the autism spectrum in 2014 to promote acceptance



Acceptance & Inclusivity

- ▶ We as chaplains have the opportunity to model that radical acceptance and inclusivity.
- ▶ Each patient, each family member, each experience carries inherent worth and dignity.

Practical Interventions



Tools we can use

- ▶ Concrete language
 - ▶ Don't use 10 words when 4 will do.
 - ▶ *"I'm feeling curious about what's going on inside you right now."*
 - ▶ Better choice: **"How do you feel?"**
- ▶ Not the time for metaphors
 - ▶ Say what you mean & mean what you say
 - ▶ *"Pick up the pace"*

Tools we can use

- ▶ Prompting

- ▶ It's hard to draw words out of thin air.

- ▶ **“I feel _____.”**

- ▶ Identifies & validates

- ▶ Can give two options

- ▶ First-Then Language

- ▶ **“First we talk. Then we can pray together.”**

Tools we can use

- ▶ Visual Aids
 - ▶ Prayers in written form
 - ▶ “Point to” charts (especially handy for non-verbal patients)

Tools we can use



Tools we can use

- ▶ PECS: picture exchange communication system
 - ▶ Non-verbal patients can request things and communicate emotions
 - ▶ Laminated pictures with velcro backing
 - ▶ Likely that patient will have a binder

PECS

I want



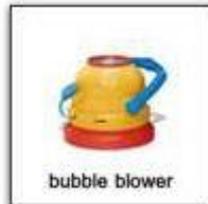
big wheel



golf



trampoline



bubble blower



sand and water table



sidewalk chalk

Behavior talks!

- ▶ Behavior = communication
- ▶ Physical cues...wincing in pain, clenched fists, wide eyes, smiling
- ▶ Vocalization...screaming, crying, moaning, giggling
- ▶ **People don't just do; they do because.**
 - ▶ Examine “problem behaviors” to see what they might be telling us

Tools we can use

- ▶ Ask!
 - ▶ Autonomy & choice
 - ▶ “Can I hold your hand?”
 - ▶ “Do you want to pray?”
 - ▶ “Can I sit with you?”

Talk to the person directly.

Tools we can use

- ▶ Assume ability and competence.

“People may communicate very differently, as well as be at very different places on the spectrum of autism, but do not assume that a person is not understanding, intellectually and emotionally, what he or she experiences.”

(Gaventa, 2008)

- ▶ **“Simple, not childish”**

What success looks like

Column:

A man with autism, behaving violently, winds up in the ER. The officers on duty respond — by singing and dancing.



Compassionate Care



- ▶ Patient Walker Hughes & Sgt. Keith Miller (left)
- ▶ Medication reaction brought him to Loyola University Medical Center in Chicago
- ▶ Walker was in the midst of a massive meltdown, but his panic was met with compassion and skill

We are capable!

- ▶ We possess the compassion and knowledge to provide outstanding levels of care to our patients.
- ▶ Pastoral care for patients with autism is not re-inventing the wheel. Rather, it is slightly modifying our existing skill set.



Thank you so
much!



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