An Introduction to Autism and Spirituality

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Brief Introduction

- **Who am I?**
  - Speech-Language Pathologist in Private Practice—27 years
  - Family members with ASD
  - Specialize in working with individuals with ASD and other neurobiological differences including ADHD, dyslexia, etc.

- **Let me get to know you?**
  - Experience with ASD?
Quick Scoping Discussion: According to the CDC (2018)

- About 1 in 59 children has been identified with autism spectrum disorder (ASD).
- ASD is reported to occur in all racial, ethnic, and socioeconomic groups. (there are disparities in rates of diagnosis, age of diagnosis, etc...)

Syndrome

Autism

Disorders
Quick Scoping Discussion: According to the CDC

- ASD is about 4 times more common among boys (1 in 38) than among girls (1 in 152).
Autism: What is It?

- A neurological difference/disorder
- A difference in how the brain is wired
- A difference in the individuals experience of the world
We think about the world in the way that we experience it to be. (Bogdashina; 2003)
Autism: How is It Defined

- (APA, 2013)
  - Deficit in social communication and interaction
  - Restricted, repetitive patterns of behavior, interests, or activities
Theories related to ASD

- Causes of ASD
  - Genetic
  - Environment
- Theories
  - Theory of Mind
  - Central Coherence
  - Executive Functioning
Strengths of individuals with ASD

- Visual Thinking
- Bottom-Up Processing
- Sustained Attention to Areas of Interest
- Excellent Memory for Details and Facts
- Ability to Thrive in a Structured, Well-Organized Environment

- Idiosyncratic Forms of Humor
- A Strong Sense of Justice, Fairness, and Right vs. Wrong
- Honesty and Loyalty
Autism Spectrum Disorders and Co-Occurring Health Difficulties

- Neurological
  - Seizures
  - Sleep
  - Autonomic Dysfunction
  - Sensory Processing Disorder
  - Intellectual Disabilities
  - Communication and Language Disabilities

- Genetic
  - Fragile X
  - Tuberous Sclerosis
  - Others

- Medical Issues
  - Feeding/Eating
  - Gastrointestinal
  - Allergies
  - Accidents/injuries/Safety
  - Dental
Co-Occurring Mental Health Difficulties

- Anxiety
- Mood Disorders (Depression, Bipolar)
- Obsessive-Compulsive Disorder
- Attention Deficit Disorder
Co-Occurring Mental Health Difficulties

- Post-Traumatic Stress Disorder
- Attachment Disorder
- Schizophrenia and Thought Disorders
- Oppositional Defiant Disorders
- Addiction including Gaming/Internet
Church Signs

- What does it mean to be welcome?
- Who is everyone?
- What is the value to individuals with Autism Spectrum Disorders and their families to be included as a part of the “everyone” who is “welcomed” into a faith community?
What is the value to the faith community to welcome individuals with ASD and their families?
“In reality, it’s likely that many persons with disabilities would not necessarily feel welcomed at these churches. Children with autism may not be included in Sunday school. Parents presenting their child with a disability for baptism or dedication hear a pledge of support from the church, but that word is often not translated into action. Unsure how to handle such rejection, some parents take turns going to church while one parent stays home with the child. Some choose to have the entire family stay home.”
Parents’ Perceptions of Congregational Supports and Participation for Children and Adults with Disabilities (Ault & Goldstein, 2012)

- Have you ever changed your place of worship because your child was not included or welcomed? 32%
- Have you ever refrained from participating in a religious activity because your child was not included? 47%
- Have you ever kept your child from participating in a religious activity because support was not provided? 56%
- Have you ever been asked to stay with your child at a religious activity so your child could participate? 55%
Parents rated a welcoming attitude toward people with disabilities as helpful (91.5%), followed by the provision of additional support to participate in regular activities (67.3%), parent support groups (48.1%), accessible materials (46.3%), and accessible facilities (46.3%).

Only 42.5% of parents described their congregations as supportive, 41.1% described their congregations as sometimes supportive, and 12.7% indicated they were not supportive.

Parents who had sons or daughters with ASD were more likely than parents of sons or daughters with mild or severe intellectual disabilities to feel less supported in their faith community.
Who is in need of spiritual supports:

- The individual with ASD
- The family of the individual with ASD
- Those working with and supporting the individual with ASD
Who is in need of spiritual supports:

- The AS/NT Couple or AS/AS Couple
- The faith community that “welcomes” the individual with ASD and their family
Autism and Spirituality

Spirituality and the expression of that spirituality bring meaning to many people's lives. Belonging to a faith-based community is one of the most common ways to engage in spirituality with others. (Gaventa, 2014)
People with mental retardation and related developmental disabilities have the right to choose their own expressions of spirituality, to practice those beliefs and expressions, and to participate in the religious community of their choice or other spiritual activities. The person also has a right to choose not to participate in religious or spiritual activity.
ISSUES: While many agencies providing services and supports recognize the right to religious freedom, they seldom include spirituality in individual planning. Nor do they often help people participate in the spiritual activities or religious communities of their choice and/or tradition. Individuals and their families also often face a mixed response from congregations, even though many congregations and faith networks have established model programs and strategies for including people with disabilities. Spiritual resources and congregations are an untapped source of community supports and inclusion, beyond the practice of faith and belief.
Autism and Spirituality

- Persons with autistic spectrum disorder were much more likely than those in our neurotypical comparison group to identify as atheist or agnostic, and, if religious, were more likely to construct their own religious belief system. (Caldwell-Harris, Murphy, Velazquez, & McNamara, 2011)
  - Why does this occur?
Key Spiritual Themes Identified by Individuals with ASD (Baldwin, et al., 2015)

- The importance of their beliefs
- Personal sources of comfort and strength
- Finding purpose in helping others
- Significance of personal connections
- Strengths-based perspectives on disability
Ways Individuals with ASD and Their Families May Need Spiritual Support

- Community participation
- Spiritual growth
  - Formally evidence-based practices
  - Informally as part of faith community
- Counseling
  - Individual
  - Family member
  - Couple-AS/NT or AS/AS
- Respite
What can communities of faith do?

- Be Proactive rather than Reactive (Newman, 2011)
- Education and Outreach
  - Education of faith community
  - Outreach to Individuals and Families of Individuals with ASD
- Provide a welcoming, accepting, inclusive environment
  - Know, and address, any community biases that may impact on the individual with ASD, or their family, attending, and fully participating, in your faith communities activities

- Provide a welcoming, accepting, inclusive environment by addressing barriers that may prevent individuals from accessing community
- Provide a “sensory-safe” environment
  - Avoid strong smells: air fresheners, incense, perfumes, strongly scented cleaning products
  - Avoid loud, unpredictable noises: Keep the volume of speakers to the lowest that is audible to all, provide headphones or sound blockers
What can communities of faith do? (Newman, 2011)

- Provide a “sensory-safe” environment
  - Provide opportunities for movement (space in the back where someone can pace, rocking chair, trampoline)
- Make routines visual: teach routines
- Differentiate materials for individuals with ASD based on their understanding
- Provide transition cues: timers, verbal cues, visual cues
What can communities of faith do?

- Explore the Hidden Curriculum of faith community
  - The hidden curriculum refers to the set of rules or guidelines that are often not directly taught but are assumed to be known (Myles, Trautman, & Schelvan, 2013)
  - What is important to your faith community and how is that communicated to individuals with ASD and their families?
  - How can these be taught/made clear to individuals with ASD?
What can communities of faith do?

- Gathering information about the individual with ASD
  - Variety of forms for this, including ones in the book: Autism and Your Church, (Newman 2011)
  - Person-Centered Planning: Person centered approaches are about discovering and acting on what is important to a person and what is important for them and finding the balance between them. It is a process of continual listening and learning, focusing on what is important to someone now and in their future, and acting on this. (SEND Guidance: Person Centred Planning Toolkit, 2015)
What can communities of faith do?


- Provide supports that will allow the individual with ASD to be included with your faith community’s activities:
  - Try to make abstract concepts more concrete (e.g., mind maps for concepts)
  - “Explain metaphor, imagery, analogy, colloquial, and contracted or stylised phrases when preaching (or discussing in bible study). These descriptive tools help many people to understand, but can be inaccessible to those with ASD and SLD. A very brief explanation of them will allow everyone to benefit from what’s said.”
What can communities of faith do?

- Provide supports that will allow the individual with ASD to be included with your faith community’s activities:
  - Use evidence-based practices that have been found to help individuals with ASD to learn (Findings and conclusions: National standards project, phase 2, 2015)
    - Behavioral supports
    - Video Modeling
    - Social Stories
    - Comic Strip Conversations
    - Peer Mentors
What can communities of faith do?

- Provide supports that will allow the individual with ASD to be included with your faith community’s activities:
  - Use evidence-based practices that have been found to help individuals with ASD to learn (Findings and conclusions: National standards project, phase 2, 2015)
    - Power Cards
    - Peer Mentoring/Modeling
    - Direct Instruction
    - 5-Point Scale
What can communities of faith do?

- Provide supports to families of individuals with ASD:
  - Respite and a “safe” and understanding space for their child
  - Develop a community of empathy, compassion, and inclusion
  - Siblings of individuals with ASD may need additional supports as their needs may go unrecognized and/or unsupported
Questions and Contact Information

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