

***Uniquely Human:
A Different Way of Seeing Autism***

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There's a quiet
revolution going on in
autism

(that's not so quiet anymore!)

Sources for Presentation

My Four Worlds of Autism

Caregiving world – 6 years as residential counselor,
20 years of parent retreat weekend, longitudinal
relationships with families

Academic/research world – SLP in Comm. Disorders
and in Psychiatry (Brown Medical School),
developer of evidence-based approach (SCERTS)

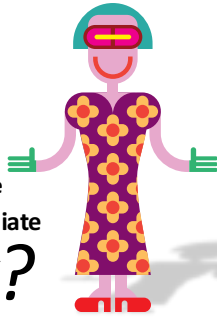
Service Provision world – SLP in schools, hospitals
and school consultant nationally/internationally

First person world of autism – sharing time, learning
from and collaborating with autistic people

Why “Uniquely Human”?

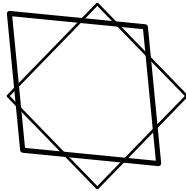
- Behavior in autism
 - Has been misunderstood/dehumanized
- Deep interests and strengths
 - referred to as obsessive
 - solution? -reduce or eliminate
- Behavior judged as inappropriate without asking

WHY?



Focus on Three Issues

1. Understanding the behavior of people with ASD - their challenges and experience
2. Debunking the belief that ASD is a tragedy for the child and family
3. Debunking the belief that ASD is only within the child or person



De-humanizing Autistic People Lovaas’ Concept of Autism (1974)

- *“Autistic children are severely disturbed. They show no signs of warmth toward others.*
- *You start pretty much from scratch when you work with an autistic child. You have a person in the physical sense — they have hair, a nose and a mouth — but they are not people in the psychological sense”*

(Psychology Today, 1974)

Common descriptions of the behavior of persons with autism

- Non-compliant/stubborn
- Manipulative
- Rude
- Bizarre/Avoidant
- Deviant/Challenging
- Obsessive/Self-stimulatory
- Non-functional
- Meaningless/Irrelevant
- Perseverative
- Non-communicative

Phrases that Blame the Child

- "It's a control issue"
- "Non-compliant behavior"
- "She's being manipulative"
- "He's so aggressive"
- "He's just stimming"
- "He understands everything – he's just trying to get out of _____"
- "She doesn't need supports"

***"Self-stims" =
Self-regulation"***

- Stephen Shore, Ed.D.

"I love when science catches up to the autistic experience."

- Judy Endow

Autistic Writer,

Social Worker and Consultant

The notion of autism as a tragedy

- "Autism is a lost, hellish world"
D. Kirby, from his book, *Evidence of Harm*
- Robert Kennedy Jr. Quote (4/7/15) "I employed the term "holocaust ...as I struggled to find an expression to convey the catastrophic tragedy of autism which has now destroyed the lives of over 20 million children and shattered their families."

vs. the notion of autism as a tragedy

- "Some call it autism, others call it despair and sorrow. I happen to call it hope, beauty and fascination".
- Mother of Michael, 9 years old, from her blog
- "Asperger's is not a disease. It's a way of being. There is no cure, nor is there a need for one. There is, however, a need for knowledge"
- John Elder Robison, adult with AS
- "The people who have been most helpful to us are those who do not take away our hope. We have learned to keep away from the 'doom and gloom' crowd".
- Father of 8 year old boy

What We've Learned from Experience and Research

- There is no such thing as autistic behavior - it is all human behavior.
 - Behavioral patterns best understood as reactions to confusion, stress, anxiety, or even great excitement and joy
 - are often attempts to communicate, regulate one's emotions and cope
 - We need to ask WHY?
- *****
- Passions are a well-spring of opportunity and offer many possibilities

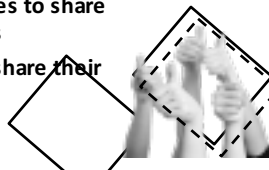
Actions that schools can take

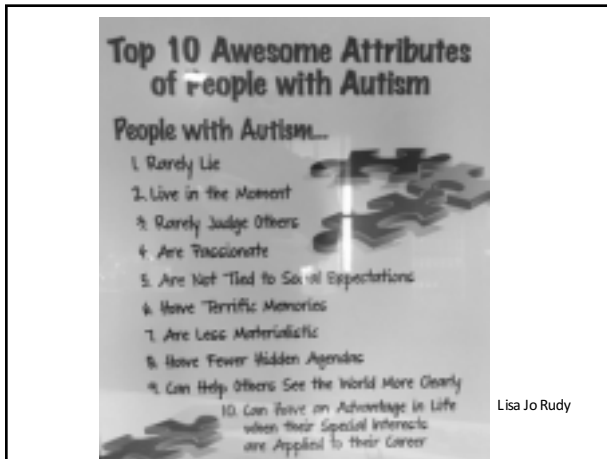
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- Disability and autism awareness programs
 - Autistic students talking about autism, and providing input for their school programming
 - Parents/family members talking with students and staff
 - Autistic adults consulting to schools



Actions that schools can take

- Celebrate success and "show off" abilities of students with ASD
- Talk and teach about famous, accomplished people with ASD (Temple Grandin, A. Einstein, Daryl Hannah)
- Share positive stories from the media
- Invite parents of graduates to share their success stories
- Invite autistic people to share their stories





Myth: Autism is only within the child – the disease model of autism

- **Progress – focuses on “recovery” - changing the behavior of the person so that DSM criteria are no longer met**
- **Goal is to approximate what some call “normal” behavior (but “normal” is a setting on a dryer)**

“De-Pathologizing” Autism
How we interpret and understand behavior

Autistic Behavior → Human Behavior

Obsessions → Enthusiasms, passions

Insensitive → Hypersensitive

Not interested in relationships → Challenges in understanding and trusting others


ASD as Tragedy → ASD as Difference


“De-Pathologizing” Autism
How we provide education and support

Control behavior → Build self-determination
 Train Compliance → Enhance initiation and self expression
 “Deficit checklist” → ID and build strengths
 Train rote skills → Authentic Progress
 Change people with autism → Change *our* behavior, attitudes and supports

**What we’ve learned –
 Autism is a shared HUMAN Experience**

This shared experience presents

1. Challenges 

2. Tremendous potential for growth for the individual, families, school communities and society 

**Autism is a SHARED
 Human Experience**

- Becomes part of the fabric of life for all involved – educators, families and those with autism
- Development is life-span - no ceiling on potential for growth
- “A person with autism is more a product of their life’s experiences than the autism”
 – Michael John Carley


Autism is a SHARED Human Experience

Becomes part of the fabric of life for all involved

Educators Service Providers Families Those with Autism



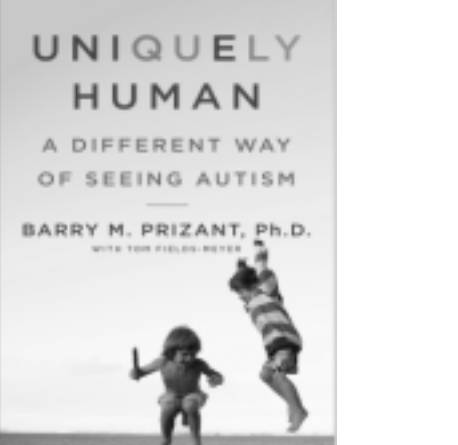
Why a Uniquely Human Perspective?



A deeper understanding builds trust with people with ASD and families

Makes our communities more humane and caring

Makes us all better people



For more information and resources:

WWW.BARRYPRIZANT.COM
WWW.SCERTS.COM

Uniquely Human:
A Different Way of Seeing Autism
(Simon & Schuster, 2015)

Uniquely Human On-Line Course
