

SELF-ADVOCACY AND DISCLOSURE FOR PEOPLE ON THE AUTISM SPECTRUM
 PRACTICAL SOLUTIONS FOR A VITAL PART OF SUCCESS

March 20, 2009
 Philadelphia, PA

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INTRODUCTION AND A LITTLE BIT ABOUT ME

A LITTLE BIT ABOUT ME
 Introduction



The Autism Bomb



Loss of speech & tantrums

Self-stims

Environmental withdrawal

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DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS IV-TR

American Psychiatric Association **2000**

DIAGNOSTIC AND STATISTICAL MANUAL OF MENTAL DISORDERS
FOURTH EDITION
TEXT REVISION
DSM-IV-TR™

Reframe

- Communication
- Socialization
- Restricted Interests

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THE AUTISM SPECTRUM

Severe Moderate Light

Ask and Tell: Self-Advocacy and Disruption in Autism Treatment

Increasing Variability of Pres

Kanner's PDD-NOS HFA/AS

Rosin, D. (1987). "Rosin wedge". From Aspergers: What we have learned in the '90s conference in Westboro, MA. Used with permission.

Twice Exceptionality

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INNER AND OUTER SENSES
SENSORY VIOLATIONS

- Sight:** - Fluorescent lights
- Hearing:** - Chirping birds, - Ticking clocks
- Vestibular (Inner ear):** - Hypo → Spinning/Hyper → Gravitational Insecurity
- Proprioceptive (Muscles & joints):** - Deep pressure, Under mattresses, Weighted blankets, Love airplanes but they mess w/Vest & Prop senses
- Taste:** - Bland foods
- Smell:** - Kissing Dad - Coffee and beard
- Tactile:** - Haircuts

Brave little kids

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CHARACTERISTICS OF CHILDREN WITH AUTISM SPECTRUM CONDITIONS

Overly sensitive to loud noises...
 Difficulty with hair washing and brushing...
 Problems with handwriting...
 Always "on the go"..
 Only likes certain types of clothing...
 Clumsy...
 Picky eater...
 Bumps into people in line...
 Difficulty paying attention...

Adapted from Myles, Cook, Miller, Rinner & Robbins. (2000). *Asperger Syndrome and sensory issues: Practical solutions for making sense of the world*. Shawnee Mission, KS: Autism Asperger Publishing. P. 5.

A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 4

AGE	0	1.5	2.5	4	6	8	10	13	19
E	Typical development	Autism bomb hits	Putnam evaluation of atypical development	Enter Putnam					
V	Turn over at 3 days	Withdrawal from environment	at, strong autistic tendencies & psychotic	Condition improves to "neurotic"					
E	Rapid physical and motor development	Tantrums	Early entry into	The wonderful world of watch motors					
N				Echolalia and return of speech					
T				Eating baby food					
S									

Self Awareness

SUCCESS WITH AUTISM

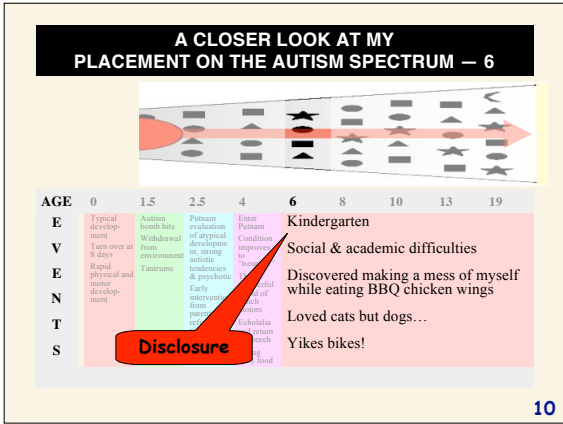
Set the Stage for Self-Determination

Acting as the primary casual agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference (Wehmeyer, 1994).

Condition improves to "neurotic"
The wonderful world of watch motors

Self Awareness

Which Sets the Stage for Disclosure...



DISCLOSURE FOR PEOPLE WITH AUTISM

C H A L L E N G E

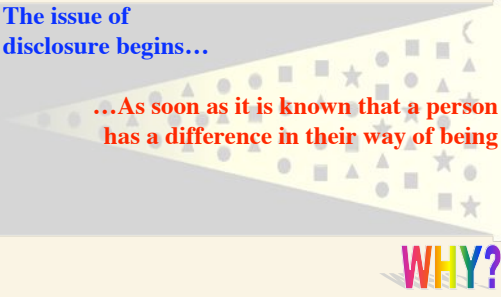
What
 about
 the Autism Spectrum
 makes
 it
 particularly
 challenging
 to
 disclose?

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D I S C L O S U R E

The issue of disclosure begins...

...As soon as it is known that a person has a difference in their way of being



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LIVING IN TODAY'S WORLD

REALITY CHECK

Most people are busy with living

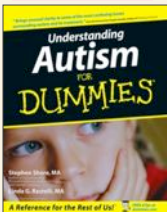
Most people are not in the mindset of accommodating people with differences

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FOUR STEPS TO DISCLOSURE

Self-Determination → Disclosure → Self-Advocacy

1. Make the child aware of their strengths and challenges through verbal, pictorial, and other communication.
2. "Rack up" strengths and challenges.
3. Non-judgementally compare characteristic with other role models.
4. Present the label summarizing a condition rather than a name for a set of deficits.
5. Making ones needs known in a way that others can understand and comply; hopefully in a proactive manner.



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SELF-ADVOCACY FOR PEOPLE WITH AUTISM

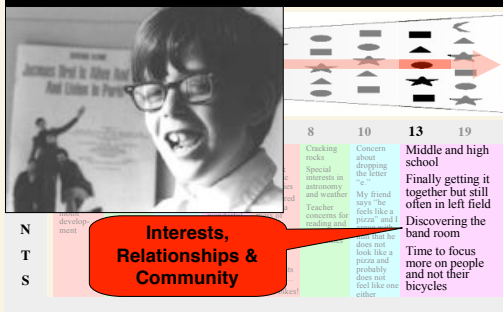
SELF-ADVOCACY DEFINED

Self-advocacy involves knowing when and how to approach others in order to negotiate desired goals, and in order to build better mutual understanding, fulfillment, and productivity.

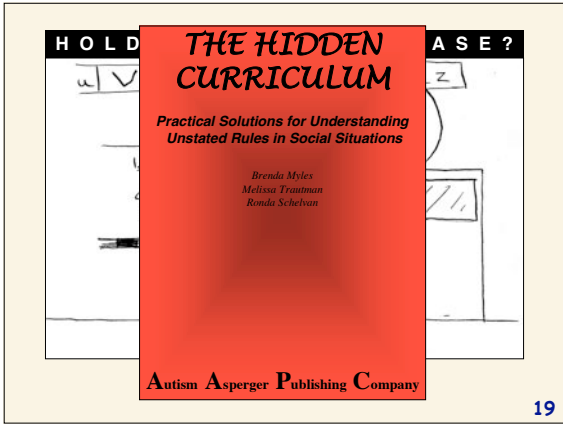
Successful self-advocacy often involves an amount of disclosure about oneself that carries some degree of risk, in order to reach a subsequent goal of better mutual understanding.

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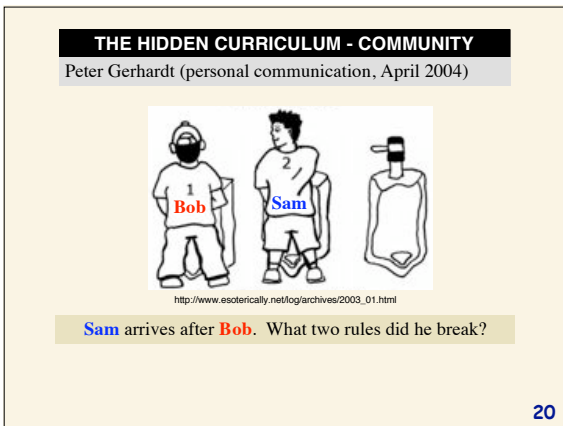
A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 13



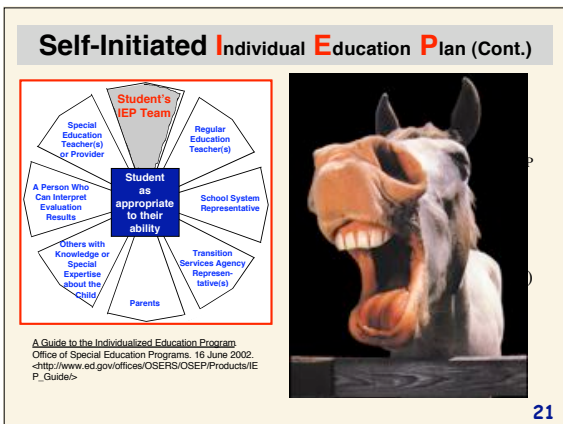
18



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Self-Initiated Individual Education Plan

To my IEP Team,

I like the way Mr. Dowd teaches math. He makes it fun and easy for me. Mrs. Sugarman's English class is very difficult. I don't understand when she diagrams sentences on the board and the scratching of the student pencils during writing time makes it very hard for me to concentrate.

*Truly yours,
Joey*

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SIX STAGES TO SELF-ADVOCACY

4. **Moral Support:** Partner continues to assist with the preparation. The advocate does most of the talking with the partner nearby to assist if needed.

5. **Taking the Lead:** The advocate leads the entire process with assistance from the facilitator but only under the self-advocate's direction.

6. **Independent Self-Advocacy:** The advocate undertakes all the preparation, presentation, and evaluation in a completely independent manner.

Adapted from Sheryl K. "Help me help myself," in Stephen Shore (Ed.), *Ask and Tell: Self-advocacy and disclosure by students with autism spectrum*. Shawnee Mission, KS: Autism Asperger Publishing Company, p. 35.

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Helping a Samantha Advocate for Herself - Case Study

— Six Stages of Self-Advocacy —

A 13-year old student in an inclusive classroom. Samantha has been coming home crying for the past week. In your observation you see that she squirms as they lightly touch her arms and get blamed for the incident. Samantha and classroom staff are working on watching Samantha's behavior so she can eventually advocate for herself.

Previously, you would have worked with Samantha's homeroom teacher about how others with tactile hypersensitivity. As part of Samantha's team, you will work on self-advocacy.

- Choose one of the six stages of self-advocacy and...
 - A. describe how you would help Samantha for her self-advocacy effort, and
 - B. describe what the advocacy effort will look like.



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THE ADULT YEARS

A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — Adult

Paradigm shift from being advocated for to advocating for one's self

Professor of Special Education at Adelphi University 32

DON'T LET THIS HAPPEN...

Special Education is **ALL DONE!!**

I want to be just like **EVERYONE ELSE**

OOPS!!!!!!

Well...

Maybe I **DO** need to find the Office of Student Support

Paradigm Shift From Being Advocated for to Self-Advocacy

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DEVELOPING A SELF-ADVOCACY PLAN

MY ADVOCACY PLAN Name _____

SCAN: Where is the challenge?		
1. Sensory	Perception of the environment	
2. Cognitive	How we think	
3. Socio-emotional	Social cues and how we feel	
ADVOCACY:		
Explaining your needs		
DISCLOSURE:		
Giving the reason why		

<p style="text-align: center;">SCAN Challenge</p> <p>What is causing the difficulty?</p>	<p style="text-align: center;">ADVOCACY Explaining your needs</p> <p>...promoting greater understanding and in a way the other can provide assistance</p>	<p style="text-align: center;">DISCLOSURE The reason</p> <p>Partial – Note specific characteristic affecting a situation only</p> <p>Full – Diagnosis</p>
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S U C C E S S W I T H A U T I S M

"Brings unusual clarity to some of the most confusing issues surrounding neurotypic disorder and its treatment."

Understanding Neurotypicals FOR DUMMIES

- Learn to decode nonspectrum behavior
- Educate children on radical acceptance of differences
- Successfully communicate without eye contact!



A Reference for the Rest of Us!

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IN CLOSING...

S U C C E S S W I T H A U T I S M

Definition

If you are productive and fulfilled with your life you are probably successful

It's all in the journey

You are exactly where you need to be right now

