Talking about Diagnosis with Your Child on the Spectrum

Lynda Geller, Ph.D.
Spectrum Services
Should I tell my child?

Absolutely, but........

When he or she is developmentally ready

• To understand
• To use the information
• To notice social differences
• To make an informed decision about disclosure

But.......  

Have not suffered extensively from the ignorance
How do I start?

Young children

• Begin by discussing differences
  – Different preferences
  – Different genders, ages, hair color, etc.
  – Different skills
  – Different problems
Strengths for Small Children

I Am Utterly Unique
Celebrating the Strengths of Children with Asperger Syndrome and High-Functioning Autism

Elaine Marie Larson
Illustrated by Vivian Strand
How do I start?

Around 7 or 8 years

• Notice if they seem to understand or comment on differences independently

• Explore if they can keep a secret

• Notice if they want to know why they have special help or are in a special group

• Have them describe people they know and how they are different physically, their interests, or their personalities
The Attributes Activity
Tony Attwood

Child with parents or family activity

Parents begin by listing their own strengths and challenges as QUALITIES and DIFFICULTIES

Child or other family members add to the list

Start a list from scratch to model the process from the beginning for the child

Parents model insuring this is a kind and positive activity
The Attributes Activity

QUALITIES
• Honest
• Liked by adults
• A dependable friend
• Specially sensitive hearing
• Kind
• Photographic memory

DIFFICULTIES
• Handwriting
• Losing my temper
• Coping with changes
• Making friends
• Tolerating loud noise
The Attributes Activity

Do this activity a few times in order to generate a list of characteristics that

• Promote the child’s self esteem

• Go with your list of the child’s spectrum characteristics
The Attributes Activity

- Have ready a profile of someone famous thought to be on the spectrum (relevant if possible)
- Discuss how the child’s positive traits are similar and that the positive traits are because the person has Asperger Syndrome (or other spectrum diagnosis)
Famous People

- http://www.asperger-syndrome.me.uk/people.htm
The Attributes Activity

- Before the discussion, have ready a list of more than one coping strategy or activity designed to address the difficulties of the child’s list. HOME and SCHOOL

- Discuss how these difficulties are because of Asperger Syndrome (or other spectrum diagnosis)

- Discuss how this is a difference with wiring or how we are put together, not a defect.
The Attributes Activity

- Gently discuss how the particular differences can affect friendship, learning, emotions, and self esteem.

- Quickly move to a discussion of strategies for each difficulty.

- Use a blackboard, easel, or paper mounted to the wall with 3 columns: QUALITIES, DIFFICULTIES, COPING STRATEGIES
The Attributes Activity

- Have a discussion of some of the best coping strategies and have the child circle favorites that may or may not have ever been used.
- Take out your own pages and circle parental favorites that have been successful.
Disclosure

- One reason to hesitate is the child’s understanding of the disclosure process.

- Understanding disclosure is a developmental process. Can the child keep a secret? How long? Is there sufficiently developed theory of mind to understand who is trustworthy and who is not?
Levels of Self Disclosure

- Public
- Personal
- Private
- Secret
Levels of Disclosure

- Public: I am a girl; I am 9 years old; I go to PS 21; I live in New York.

- Personal: My address is 621 E 21st Street, New York; My mother is 42 years old.

- Private: I have autism; I see a psychiatrist.

- Secret: I take Risperdal.
Circle of Support

PEOPLE WHO LOVE ME:
Louie

LOVE ME:
Mom - Dad - Denny - Nana

LIKE ME - MY FRIENDS:
Sarah - Adam - Hannah - Josh

PEOPLE WHO ARE PAID TO KNOW AND HELP ME:
Dr. Khan - Dr. Woodhall - Mr. Jake - Ms. Stuart

SHARED - Rebecca - Dave - Abby
Full and Partial Disclosure

**Full**
- I have Asperger Syndrome
- I have depression
- I was hospitalized last year
- I don’t have any friends

**Partial**
- I have trouble listening and writing at the same time
- I feel like I need to go to the nurse’s office to get some help
- I need help making friends
Later Diagnosis
Adolescent and Adult Diagnosis

- May have developed inappropriate coping mechanisms
- May have a rigid understanding of spectrum conditions
- May have much worse personal explanations for difficulties
- Most adults, when asked, wished they had known much sooner
How to Be Yourself in a World That’s Different
As Asperger Syndrome Study Guide for Adolescents
Self Advocacy Development

The first step to being able to advocate for oneself is to understand oneself

- Diagnosis
- Skill and trait patterns
- Evaluations and scores
- The Individualized Educational Plan (IEP) and student participation in it
Self Advocacy Development

Self advocacy includes

• **Competency**: The need to have an effect on the environment as well as to attain valued outcomes within it

• **Relatedness**: The desire to feel connected to others: to love and care, and to be loved and cared for

• **Autonomy**: The desire to self-organize experience and behavior and to have activity be concordant with one’s integrated sense of self
Valerie Paradiz, 2009
Integrated Self Advocacy®
Curriculum

- The Autism Community
- The Sensory Scan™
- The Social Scan™
- History of ASD
- Cultivating Strengths & Focused Interests
- Autism in the Media
- The Art of Self Disclosure
- My Advocacy Portfolio
Self Advocacy Skill Areas

- Sensory/Environmental
- Social
- Self Disclosure
- Deep and Focused Interests
Learning to Advocate for Sensory Needs

- Becoming a part of one’s own self-regulation and source of comfort
- Understanding how to advocate for environmental modifications
- Making novel or challenging situations more manageable
The Sensory Scan Worksheet

My Personal Information & Scan Location

Your Name: ____________________________  Date: ____________________________

School/Grade/Program: ____________________________  Which room or environment will you be scanning?

The Sensory Scan

1. Auditory Scan: Pay attention to the sound in this environment. Which of the following apply to you? Fill in as many details as you can in the Notes sections.

☐ Background noise is distracting  
   Notes: ____________________________

☐ Sudden loud noises  
   Notes: ____________________________

☐ Challenge with number or volume of voice(s)  
   Notes: ____________________________

☐ Other  
   Notes: ____________________________

2. Visual Scan: Pay attention to what you see or how you see in this environment? Which of the following apply to you? Fill in as many details as you can in the Notes sections.

☐ Light in room is too bright or too dim  
   Notes: ____________________________

☐ Type of light is distracting or challenging  
   Notes: ____________________________

☐ Angle of light is difficult (from above, below, etc.)  
   Notes: ____________________________

☐ Challenges reading in this environment  
   Notes: ____________________________
Learning to Advocate for Social Needs

Understanding & communicating social preferences

Becoming intimate with one’s own propensities for overload and shutdown

Making novel or challenging situations more manageable
Learning the Art of Self Disclosure

• Cross cultural communication

• Partial disclosure and full disclosure

• Disclosure as safety and self care
Deep and Focused Interests

- Using interests to self-regulate
- Using interests to structure communication or learning
- Building relationships through focused interests
Self-Determination

1. Self knowledge
2. Self-Advocacy
3. Self-Determination
4. Independence, autonomy, and quality of life
Goals for Self Determination
Wehmeyer & Field (2007)

- The person acts autonomously
- The behaviors are self-regulated
- The person initiated and responded to the event in a psychologically empowered manner
- The person acted in a self-realizing manner
Self-Determination, Quality of Life, and Independence

Self-Regulation: individuals examine their environments and their repertories of responses for coping with these environments to make decisions about

- How to act
- To act
- To evaluate the outcomes of their actions
- To revise as necessary
Empowerment: perceiving control and understanding it realistically

• Personal effectiveness
  – Believing you have the skills to influence outcomes
  – If you exercise these skills, anticipated outcomes will result

• Understanding Locus of Control in the situation
  – Assessing control and fault

• Motivation to use skills
Self-Determination, Quality of Life, and Independence

Self-realization: having a comprehensive and accurate knowledge of themselves, including strengths and limitations, to act in a manner that capitalizes on this knowledge in a positive way

Self-knowledge: develops through experience with the environment, evaluations by others, reinforcements, and realistic attributions
Self-Determination, Quality of Life, and Independence

This is a long process that starts with helping a child understand his or her individual qualities, diagnosis, strengths, challenges, and best coping mechanisms.

The goal is an independent life of quality and self-determination. There are many steps along the way for the individual, the family, knowledgeable professionals, and the autism community.