

# Talking about Diagnosis with Your Child on the Spectrum

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# 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.....

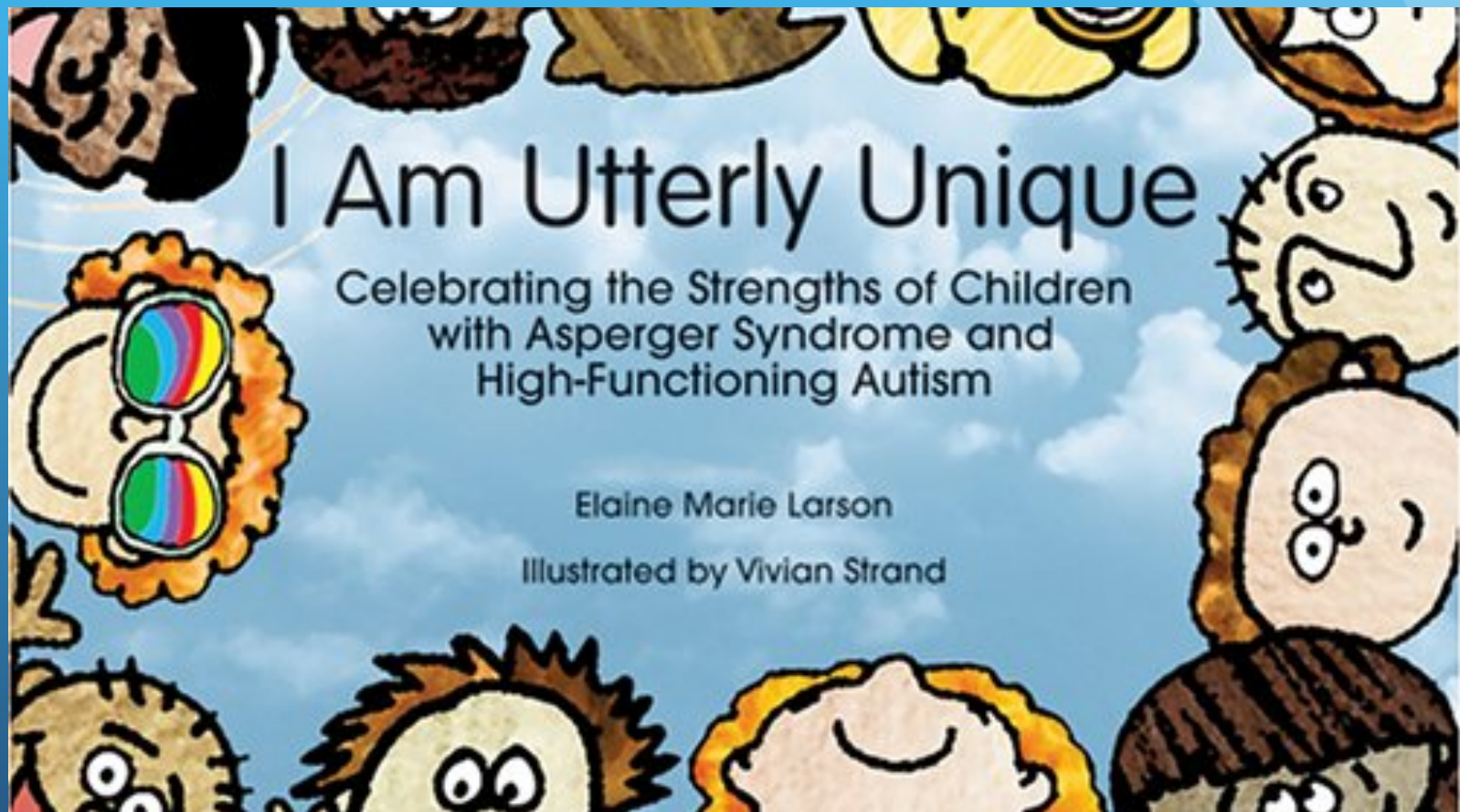
Have not suffered extensively from the ignorance

# 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



# 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

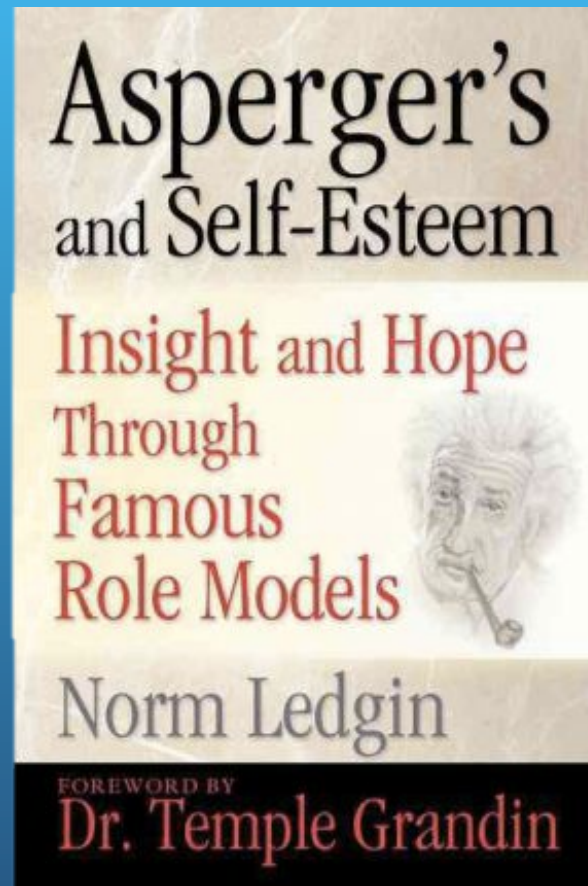
- Promote the child's self esteem
- Go with your list of the child's spectrum characteristics



# 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



# Famous People

- <http://www.asperger-syndrome.me.uk/people.htm>
- [http://en.wikipedia.org/wiki/List\\_of\\_people\\_with\\_autism\\_spectrum\\_disorders](http://en.wikipedia.org/wiki/List_of_people_with_autism_spectrum_disorders)
- [http://www.disabled-world.com/artman/publish/article\\_2086.shtml](http://www.disabled-world.com/artman/publish/article_2086.shtml)

# 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

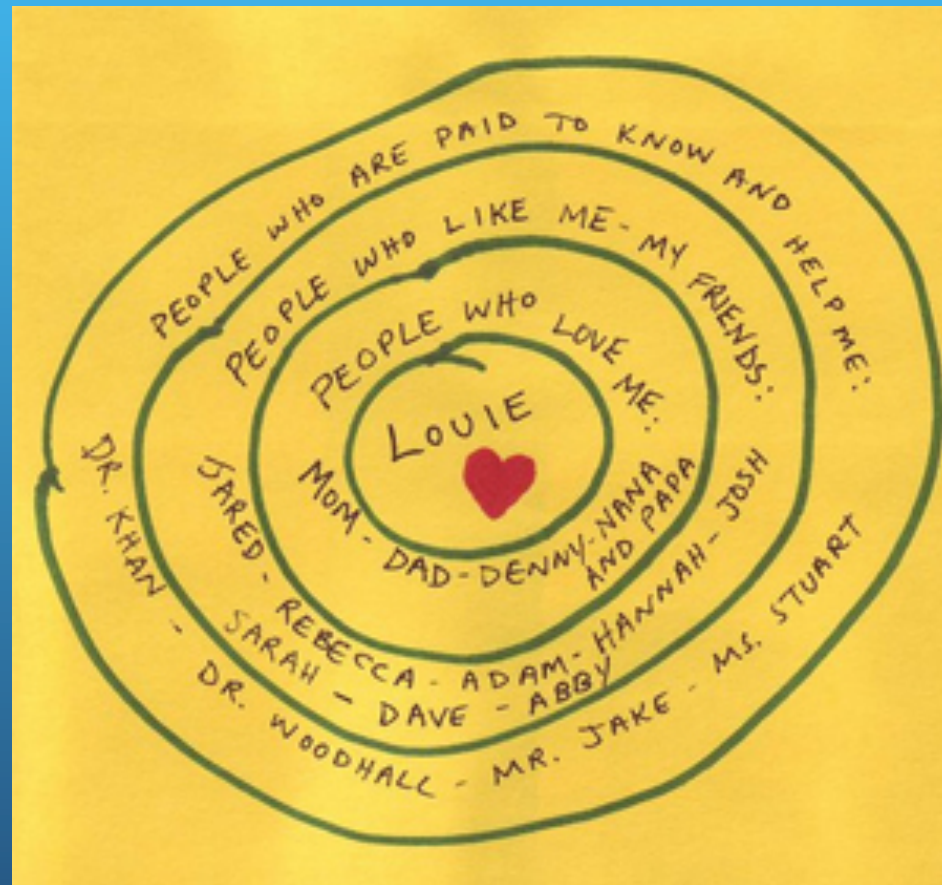
Secret



# 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 21<sup>st</sup> Street, New York; My mother is 42 years old.
- Private: I have autism; I see a psychiatrist.
- Secret: I take Risperdal.

# Circle of Support



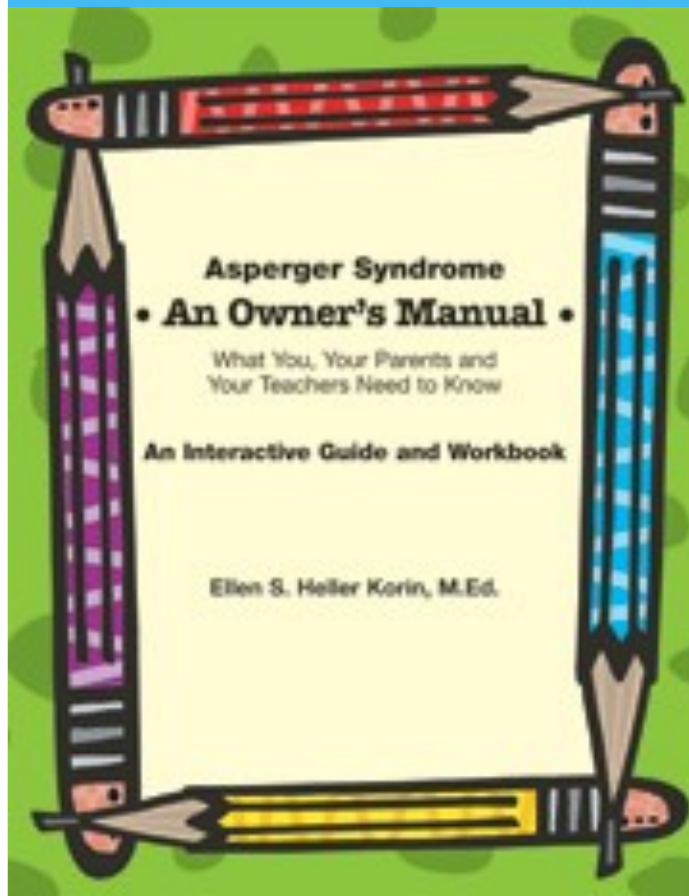
# Full and Partial Disclosure

## 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



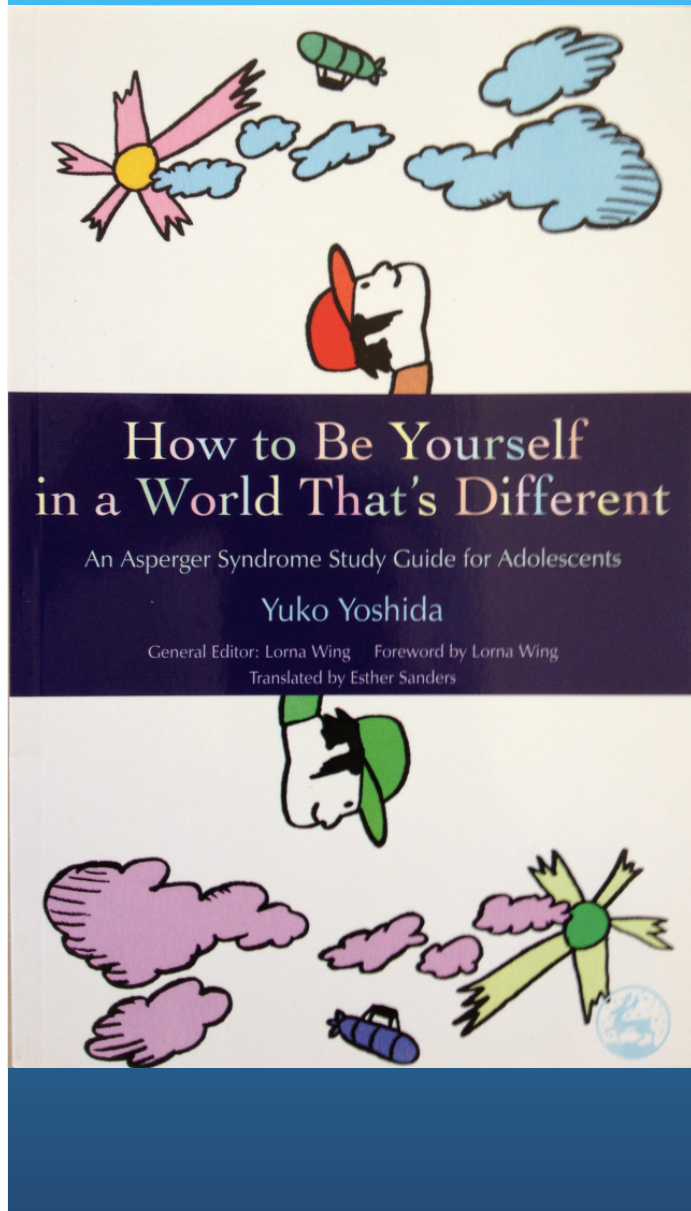
# Asperger Syndrome

An Owner's Manual, What You,  
Your Parents, and Your  
Teachers Need to Know

# 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 know 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

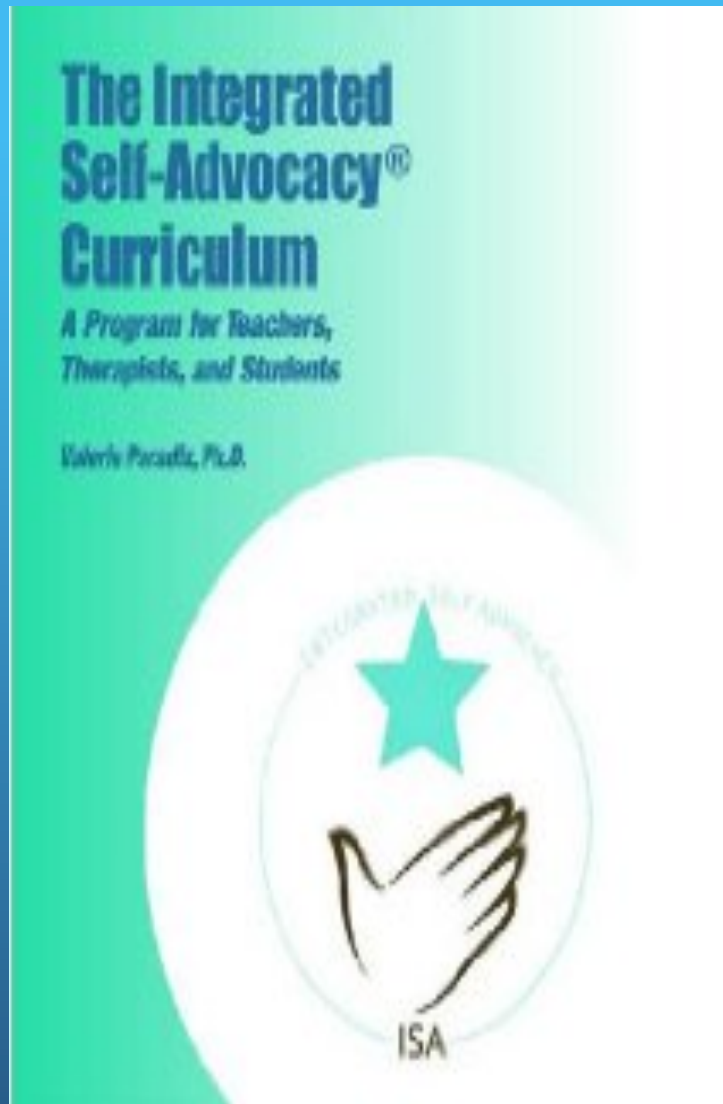
- Diagnosis
- Skill and trait patterns
- Evaluations and scores
- The Individualized Educational Plan (IEP) and student participation in it

# Self Advocacy Development

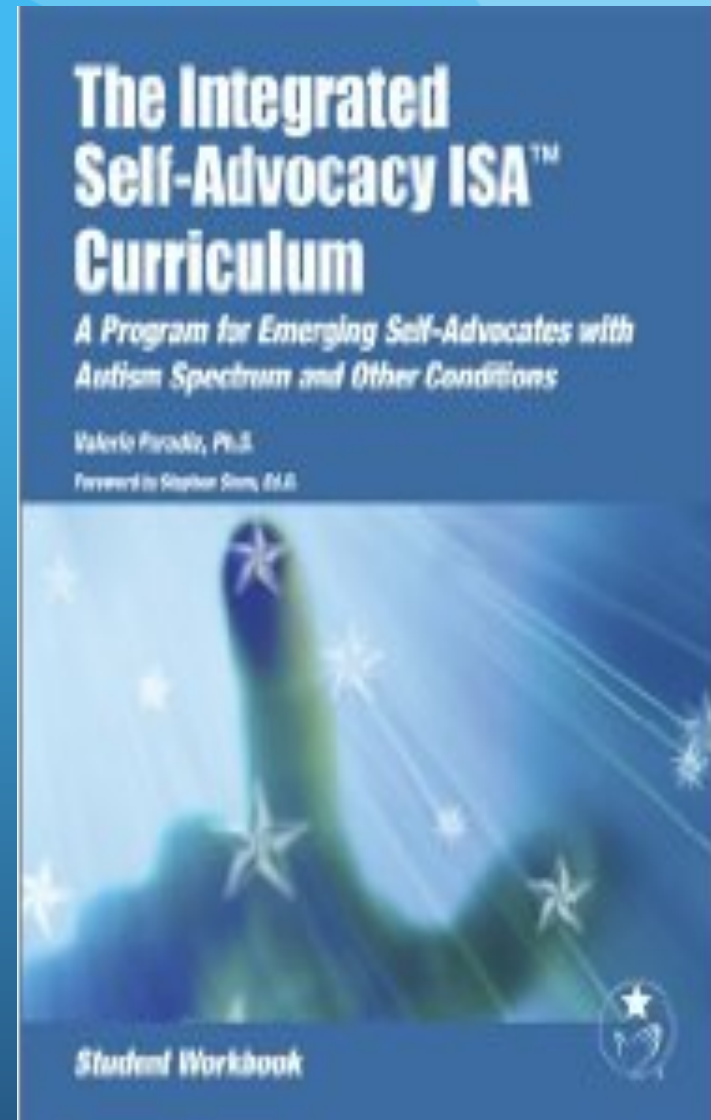
Self advocacy includes

- 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



## *The Sensory Scan Worksheet* *Integrated Self Advocacy (ISA)®*

### *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

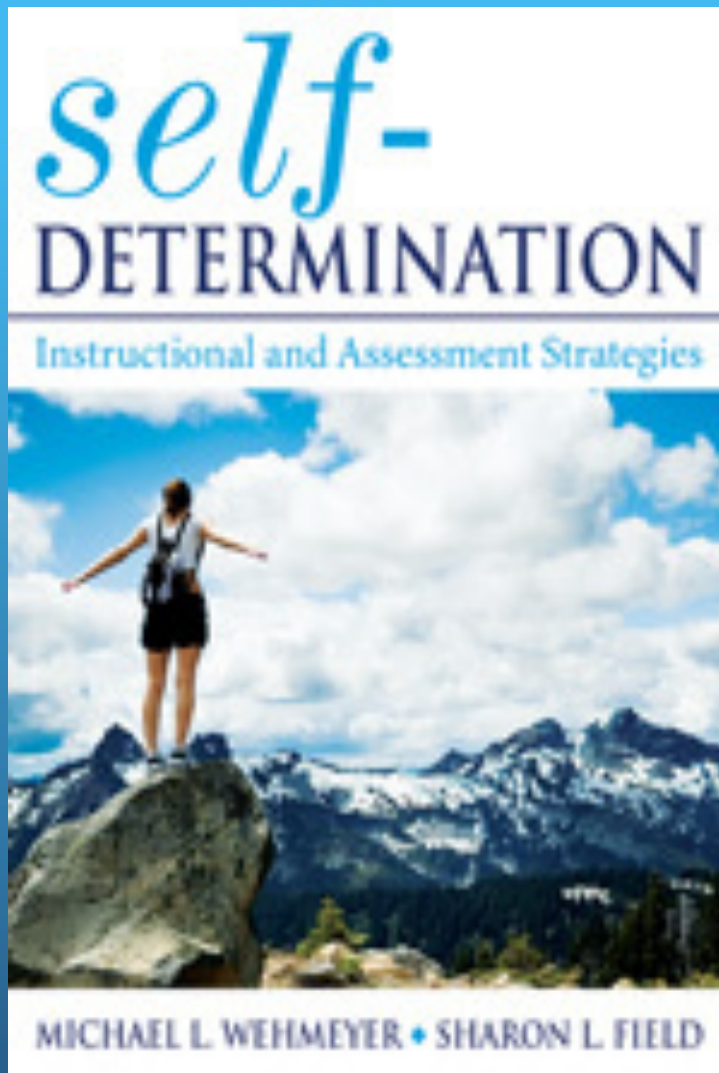
# Deep and Focused Interests

- 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 repertoires 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

# Self-Determination, Quality of Life, and Independence

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.