

# LIFE ON AND SLIGHTLY TO THE RIGHT OF THE AUTISM SPECTRUM

January 27, 2005

*Musashino Higashi Gakuen*

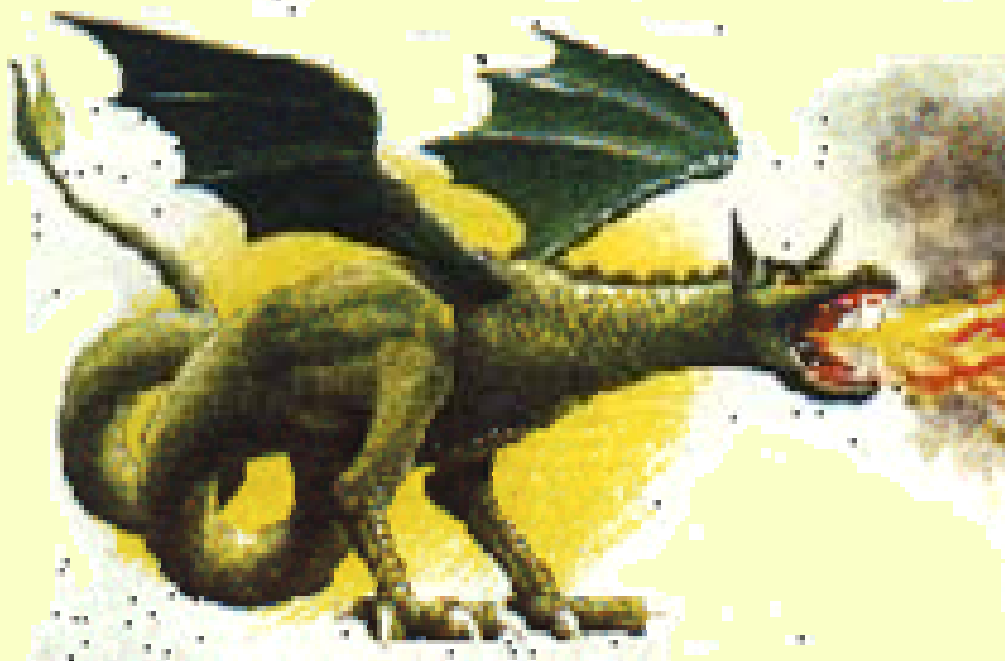
Tokyo, Japan

PRESENTED BY

**Stephen M. Shore**

[TumbaLaika@AOL.COM](mailto:TumbaLaika@AOL.COM)

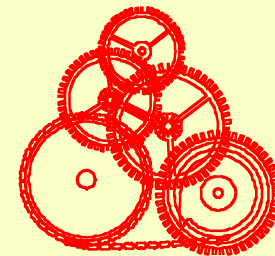
[www.AutismAsperger.net](http://www.AutismAsperger.net)



**Loss of speech  
&  
Tantrums**



**Environmental  
withdrawal**



**Spinning**

**Where oh where  
did this Autism  
come from?**

**Oh where oh where  
can it be?**

**With mysteries cut  
long and eye  
contact cut short?**

**Oh where oh where  
can it be from?**



Rapin, I. (1997). Classification and causal issues in autism. In J. Cohen and F. Volkmar (eds.) *Handbook of autism and pervasive developmental disorders*, (2nd ed). P. New York: John Wiley.

# WHAT IS AUTISM ?

**ASA  
(2003)**

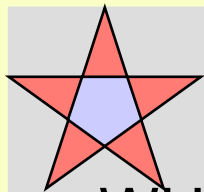
A complex developmental disability that typically appears during the first three years of life. Autism Spectrum Disorder results from a neurological condition that affects the functioning of the brain.

**DSM  
IV-TR  
(2000)**

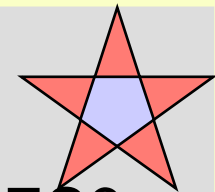
Social interaction  
Communication (but no significant clinical delay)  
Repetitive motions and restricted interests

**Miller  
(2000)**

Anything that interferes with the central nervous system getting the needed information from the environment.



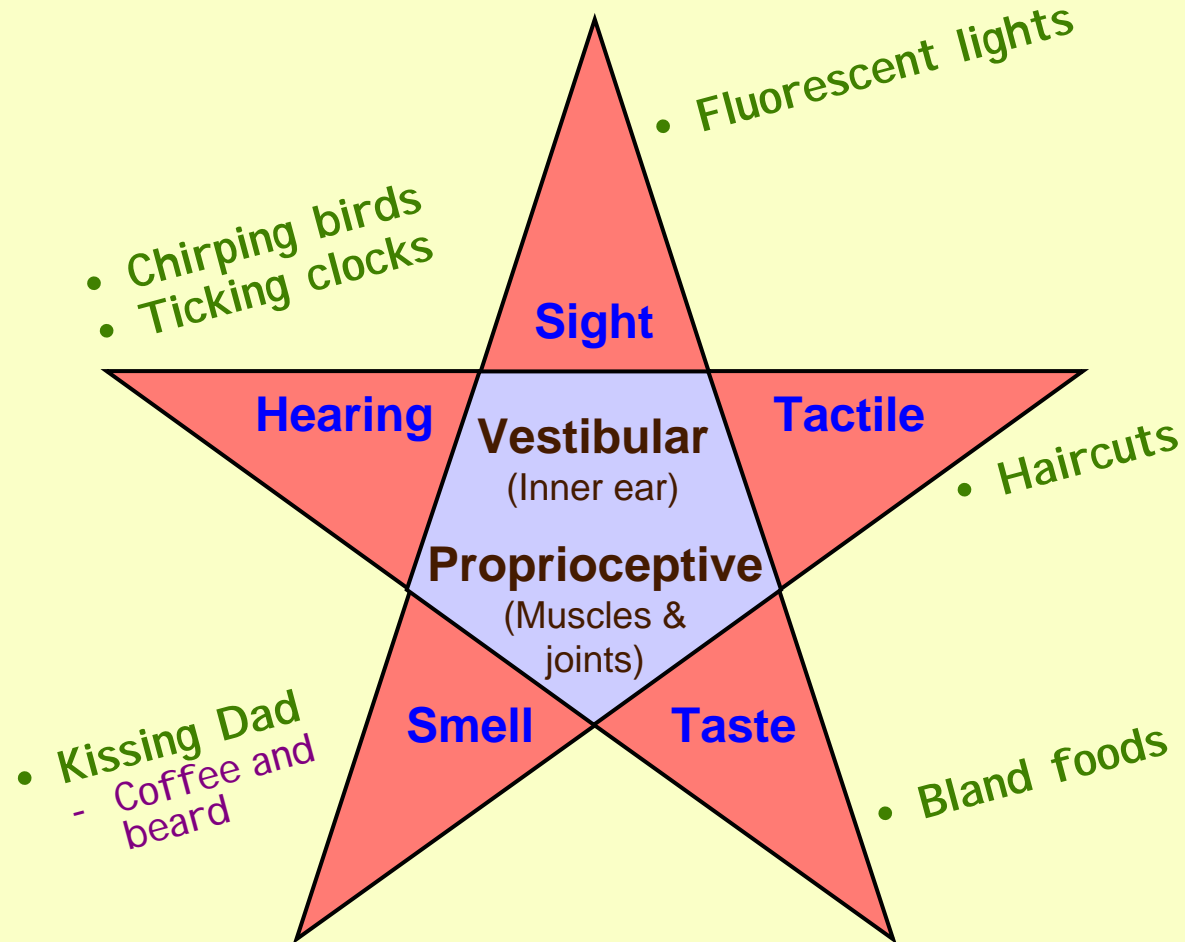
**OOPS!!!!**



WHAT ABOUT SENSORY INTEGRATION ISSUES?

# INNER AND OUTER SENSES

## SENSORY VIOLATIONS



**Vestibular:**

Hypo → Spinning/Hyper → Gravitational Insecurity

**Proprioceptive:**

Deep pressure, Under mattresses, Weighted blankets  
Love airplanes but they mess w/Vest & Prop senses

**Brave little kids**

# **SELF STIMULATORY BEHAVIOR**

## **Official Definition**

**Repetitive  
nonfunctional  
behavior**

## **Better Definition**

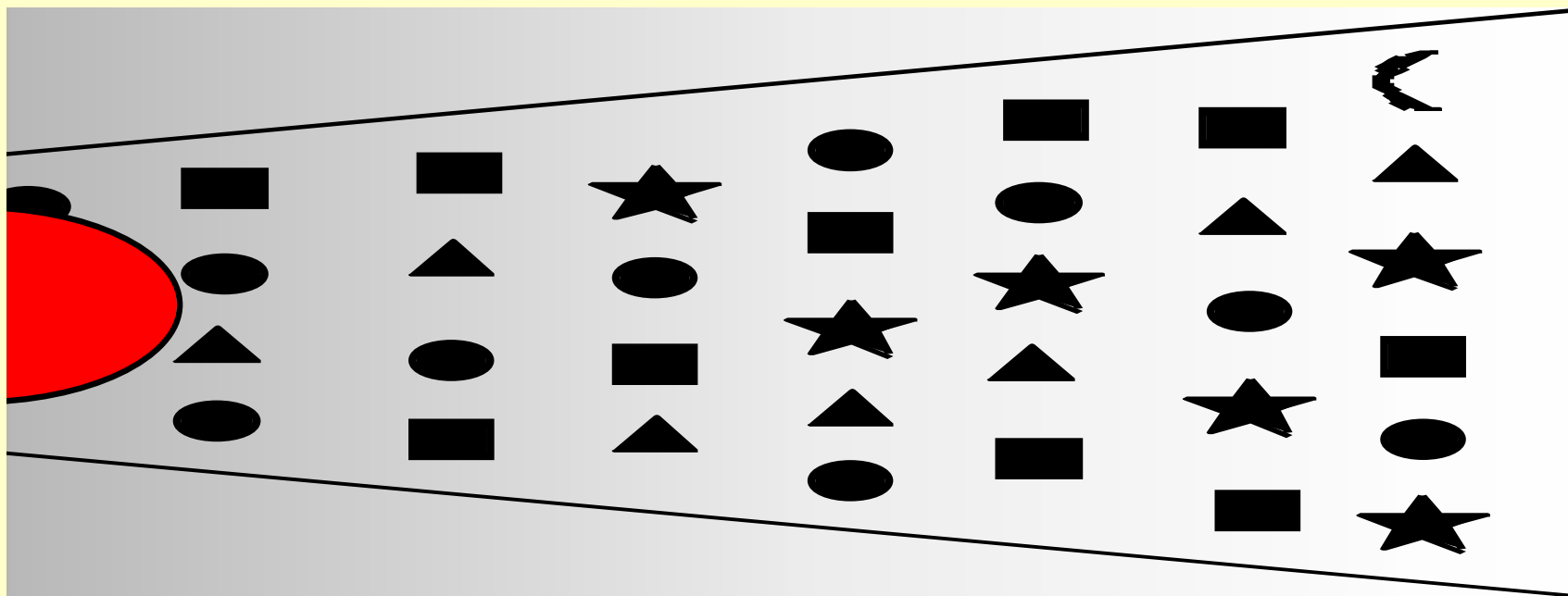
**Self-  
regulatory  
behavior**

**Most adults have learned socially acceptable stims**



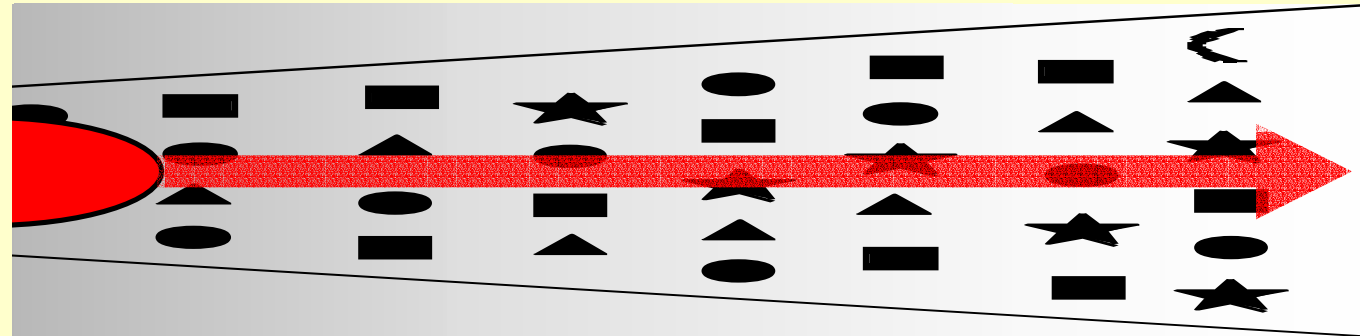
# THE AUTISM SPECTRUM

**A Closer look at my placement on the Autism Spectrum**



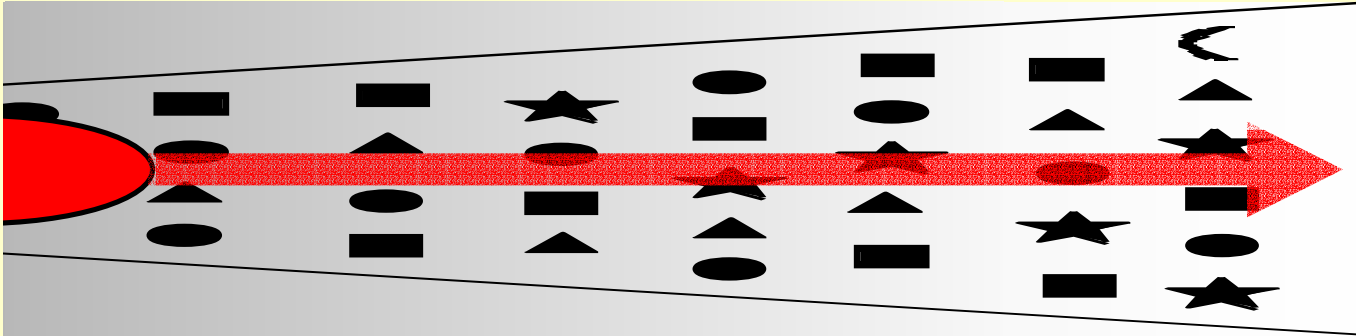


# A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM

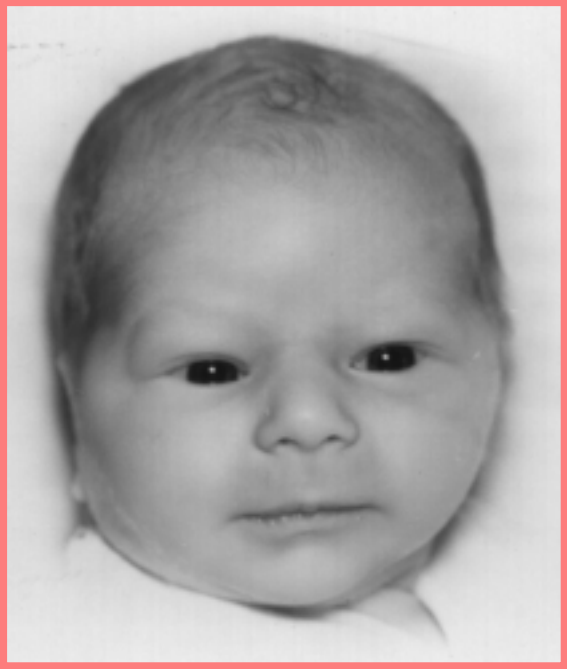


AGE	0	1.5	2.5	4	6	8	10	13	19
<b>E</b>	Typical development	Autism bomb hits	Putnam evaluation of atypical development, strong autistic tendencies & psychotic	Enter Putnam	Kindergarten	Cracking rocks	Concern about dropping the letter "e."	Middle and high school	College
<b>V</b>	Turn over at 8 days	Withdrawal from environment	Early intervention from parents who refute recommendations for removal from home	Condition improves to "neurotic"	Social & academic difficulties	Special interests in astronomy and weather	My friend says "he feels like a pizza" and I argue with him that he does not look like a pizza and probably does not feel like one either	Finally getting it together but still often in left field	More friends
<b>E</b>	Rapid physical and motor development	Tantrums	The wonderful world of watch motors	The wonderful world of watch motors	Discovered making a mess of myself while eating BBQ chicken wings	Teacher concerns for reading and math difficulties	Discovering the band room	Others really do think differently	Dating
<b>N</b>			Echolalia and return of speech	Echolalia and return of speech	Loved cats but dogs...		Time to focus more on people and not their bicycles	Utopia!	
<b>T</b>			Eating baby food	Eating baby food	Yikes bikes!				
<b>S</b>									

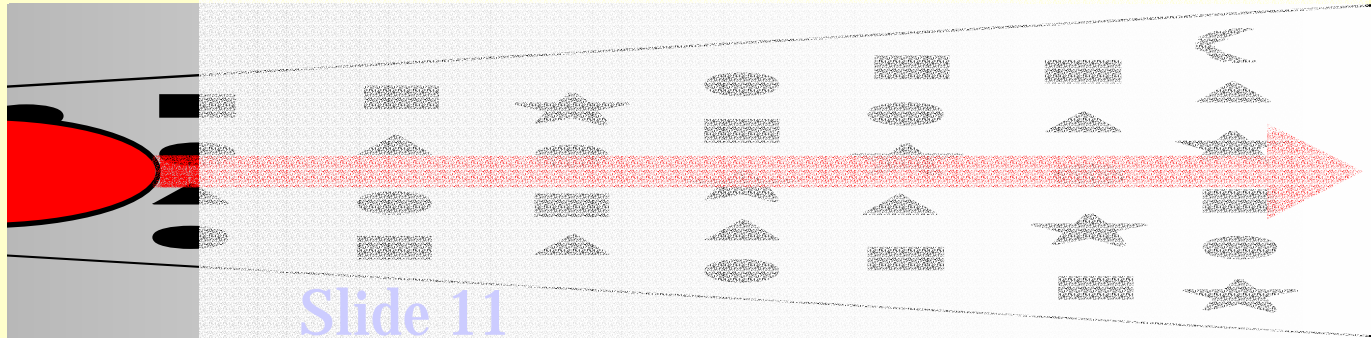
# A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 0



AGE	0	1.5	2.5	4	6	8
<b>E</b>	Typical development					
<b>V</b>	Turn over at 8 days					
<b>E</b>	Rapid physical and motor development					
<b>N</b>						
<b>T</b>						
<b>S</b>						



# A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 1.5



**AGE**    0            1.5            2.5            4            6            8            10            13            19

**E**  
**V**  
**E**  
**N**  
**T**  
**S**

Typical development  
Turn over at 8 days  
Rapid physical and motor development

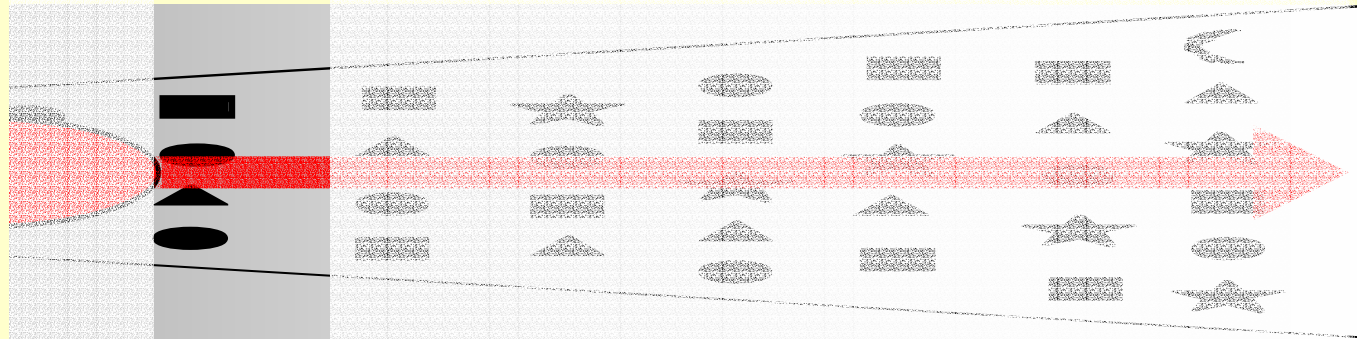
**Autism dragon hits**

**Withdrawal from environment**

**Tantrums**



# A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 2.5

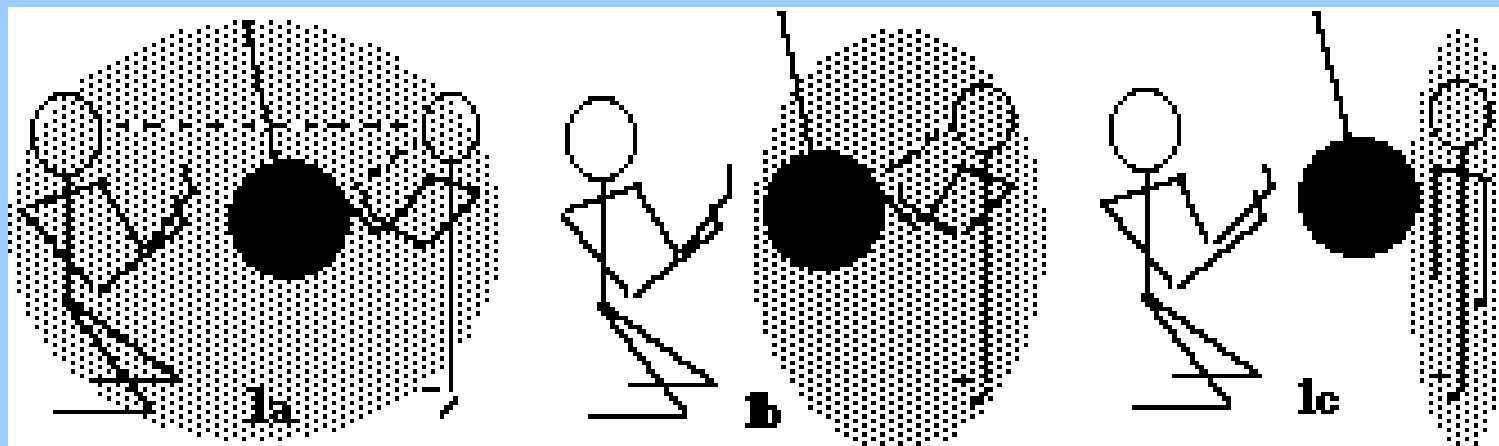


AGE	0	1.5	2.5	4	6	8	10	13	19
<b>E</b>	Typical development	Autism bomb hits	Putnam evaluation of atypical development, strong autistic tendencies & psychotic						
<b>V</b>	Turn over at 8 days	Withdrawal from environment	Early intervention from parents who refute recommendations for removal from home						
<b>E</b>	Rapid physical and motor development	Tantrums	Home-based EI emphasizing music, movement, SI, narration, and imitation.						
<b>N</b>									
<b>T</b>									
<b>S</b>									

**Zone of Intention (Miller)**

# LIMITED SPHERES OF REALITY

The Miller Umwelt Assessment Scales examines the unique way in which each child with autism experiences reality. Observation reveals the manner in which the child reacts or fails to react to different parts of a situation.



## ENVIRONMENTAL AWARENESS

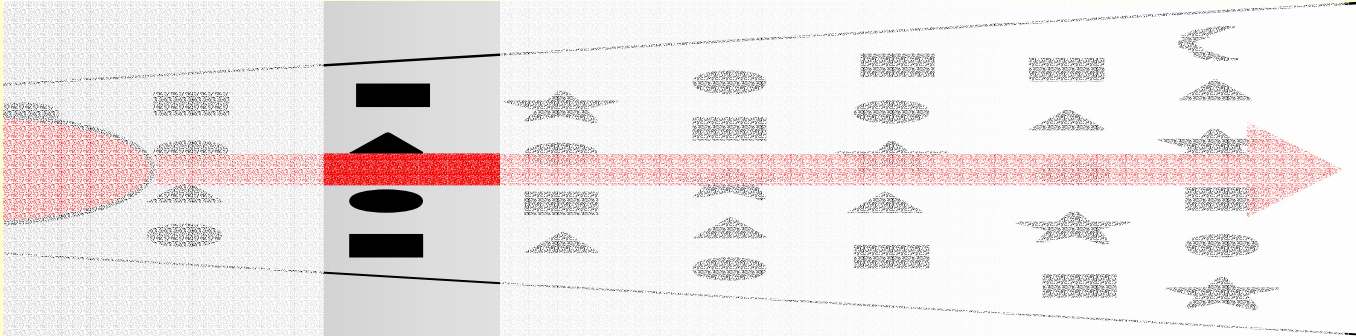
Most

Less

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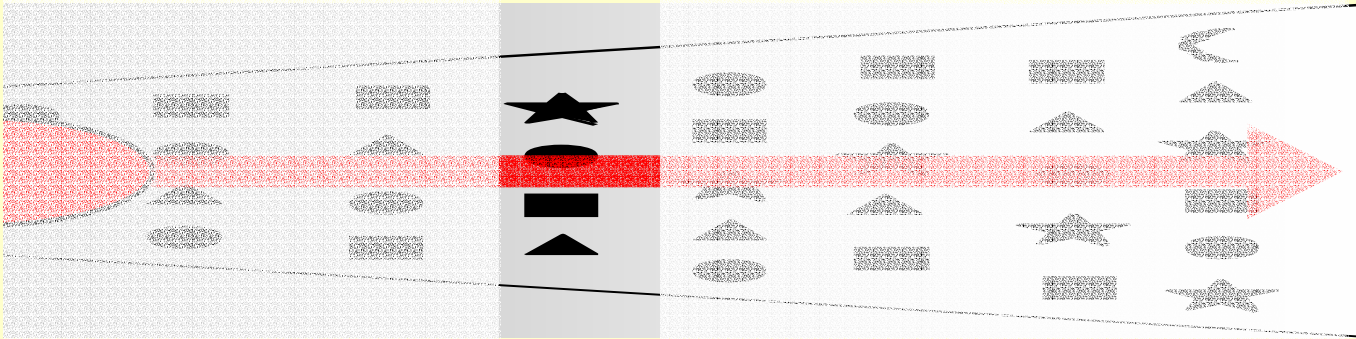
[www.millermethod.org](http://www.millermethod.org)

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



AGE	0	1.5	2.5	4	6	8	10	13	19
<b>E</b>	Typical development	Autism bomb hits	Putnam evaluation of atypical development, strong autistic tendencies & psychotic	<b>Enter Putnam</b>					
<b>V</b>	Turn over at 8 days	Withdrawal from environment	Early intervention from parents who recommend	<b>Condition improves to “neurotic”</b>					
<b>E</b>	Rapid physical and motor development	Tantrums		<b>The wonderful world of watch motors</b>					
<b>N</b>				<b>Echolalia and return of speech</b>					
<b>T</b>				<b>Eating baby food</b>					
<b>S</b>				<b>Self Awareness</b>					

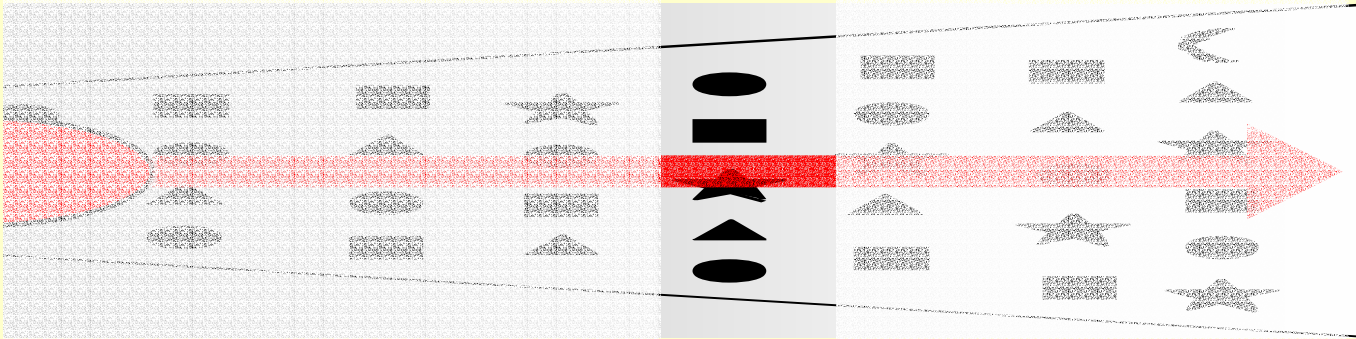
# A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 6



AGE	0	1.5	2.5	4	6	8	10	13	19
<b>E</b>	Typical development	Autism bomb hits	Putnam evaluation of atypical development, strong autistic tendencies & psychotic	Enter Putnam	<b>Kindergarten</b>				
<b>V</b>	Turn over at 8 days	Withdrawal from environment	Early intervention from parents	Condition improves "neuroti"	<b>Social &amp; academic difficulties</b>				
<b>E</b>	Rapid physical and motor development	Tantrums	Refined echolalia and return of speech	The wonderful world of echolalia	<b>Discovered making a mess of myself while eating BBQ chicken wings</b>				
<b>N</b>					<b>Loved cats but dogs...</b>				
<b>T</b>					<b>Yikes bikes!</b>				
<b>S</b>									

**Disclosure**

# A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 8



AGE	0	1.5	2.5	4	6	8	10	13	19
<b>E</b>	Typical development	Autism bomb hits	Putnam evaluation of atypical development, strong autistic tendencies & psychotic	Enter Putnam	Kindergarten	<b>Cracking rocks</b> <b>Special interests in astronomy and weather</b> <b>Teacher concerns for reading and math difficulties</b>			
<b>V</b>	Turn over at 8 days	Withdrawal from environment	Early intervention from parents who refute recommendations for	Condition improves to "neurotic"	Social & academic difficulties				
<b>E</b>	Rapid physical and motor development	Tantrums	The wonderful world of watch motors	Discovered making a mess of my					
<b>N</b>			Echolalia and re	Discovered making a mess of my					
<b>T</b>			of	Discovered making a mess of my					
<b>S</b>									

**Interests and Strengths**



# **S P E C I A L I N T E R E S T S**

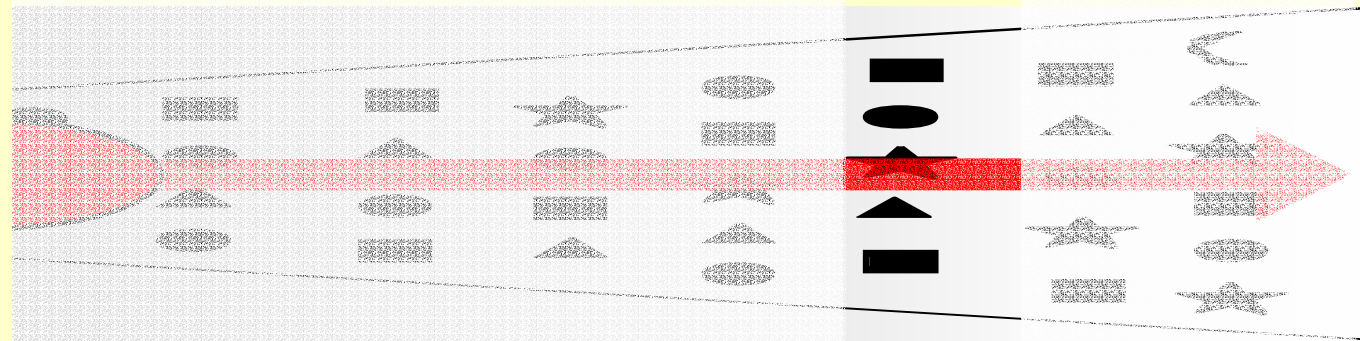
An interest of such great intensity that it interferes with daily functioning<sup>1</sup>.

## **S O M E S P E C I A L I N T E R E S T S<sup>2</sup>**

airplanes	astronomy	bicycles	earthquakes
medicine	chemistry	mechanics	electricity
electronics	computers	hardware	tools
psychology	music	rocks	geology
geography	locks	cats	dinosaurs
watches	shiatsu	yoga	autism

1. Attwood, A. (1998). *Aspergers Syndrome*. London: Jessica Kingsley Publishers.
2. Shore, S. (2001). *Beyond the wall: Personal experiences with autism and Asperger Syndrome*. Shawnee Mission, KS: Autism Asperger Publishing Company.

# A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 10



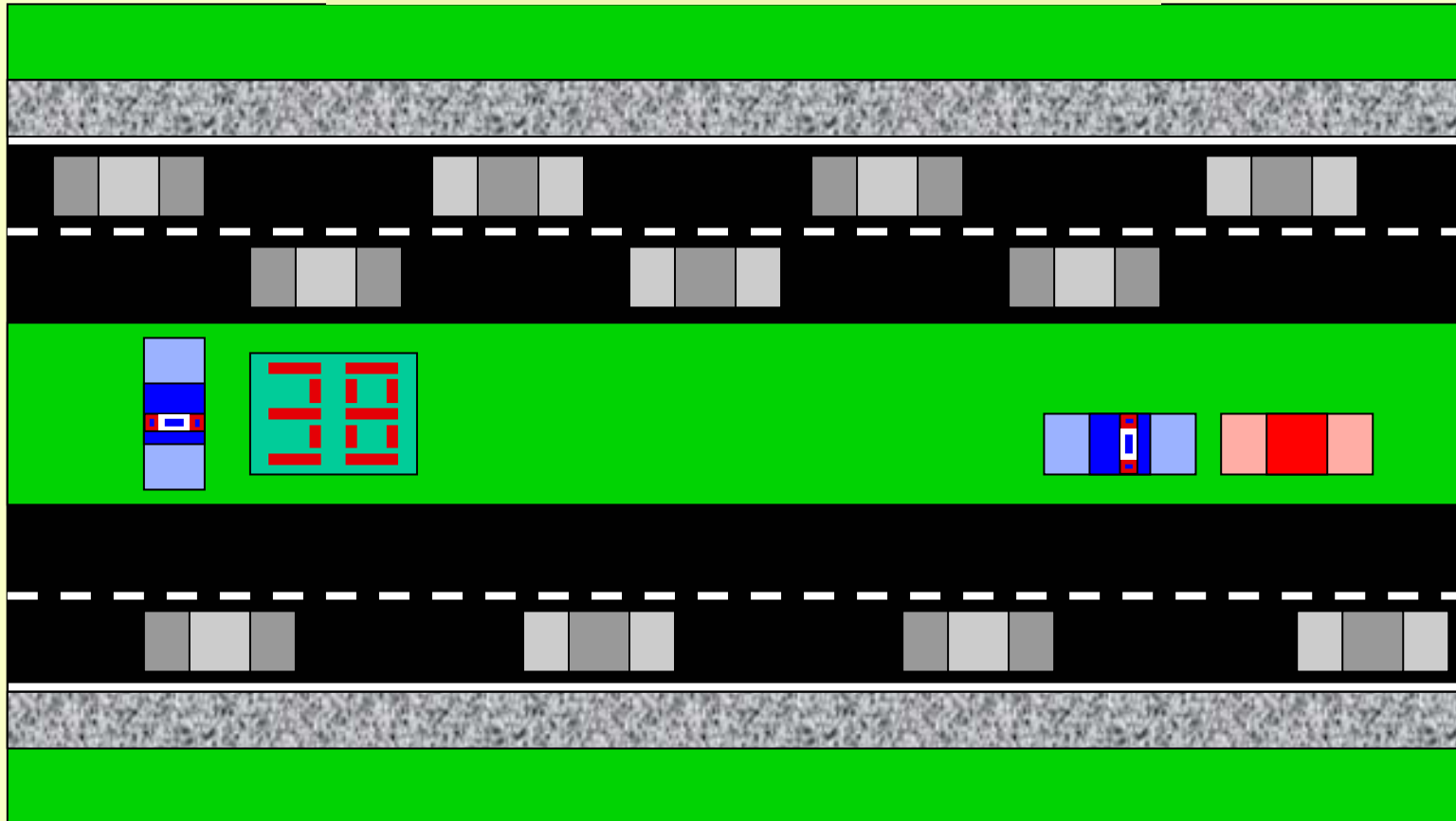
AGE	0	1.5	2.5	4	6	8	10	13	19
<b>E</b>	Typical development	Autism bomb hits	Putnam evaluation of atypical development, strong autistic tendencies & psychotic	Enter Putnam	Kindergarten	Cracking rocks	Concern about dropping the letter "e."		
<b>V</b>	Turn over at 8 days	Withdrawal from environment	Early intervention from parents who refute recommendations for removal from home	Condition improves to "neurotic"	Social & academic difficulties	Special interests in astronomy and weather	My friend says "he feels like a pizza" and I argue with him that he does not look like a pizza and probably does not feel like one either		
<b>E</b>	Rapid physical and motor development	Tantrums		The wonderful world of watch motors	Discovered making a mess of myself while eating BBQ chicken	Teacher concerns for reading and math difficulties			
<b>N</b>				Echolalia and return					
<b>T</b>									
<b>S</b>									

**Literal Thought**

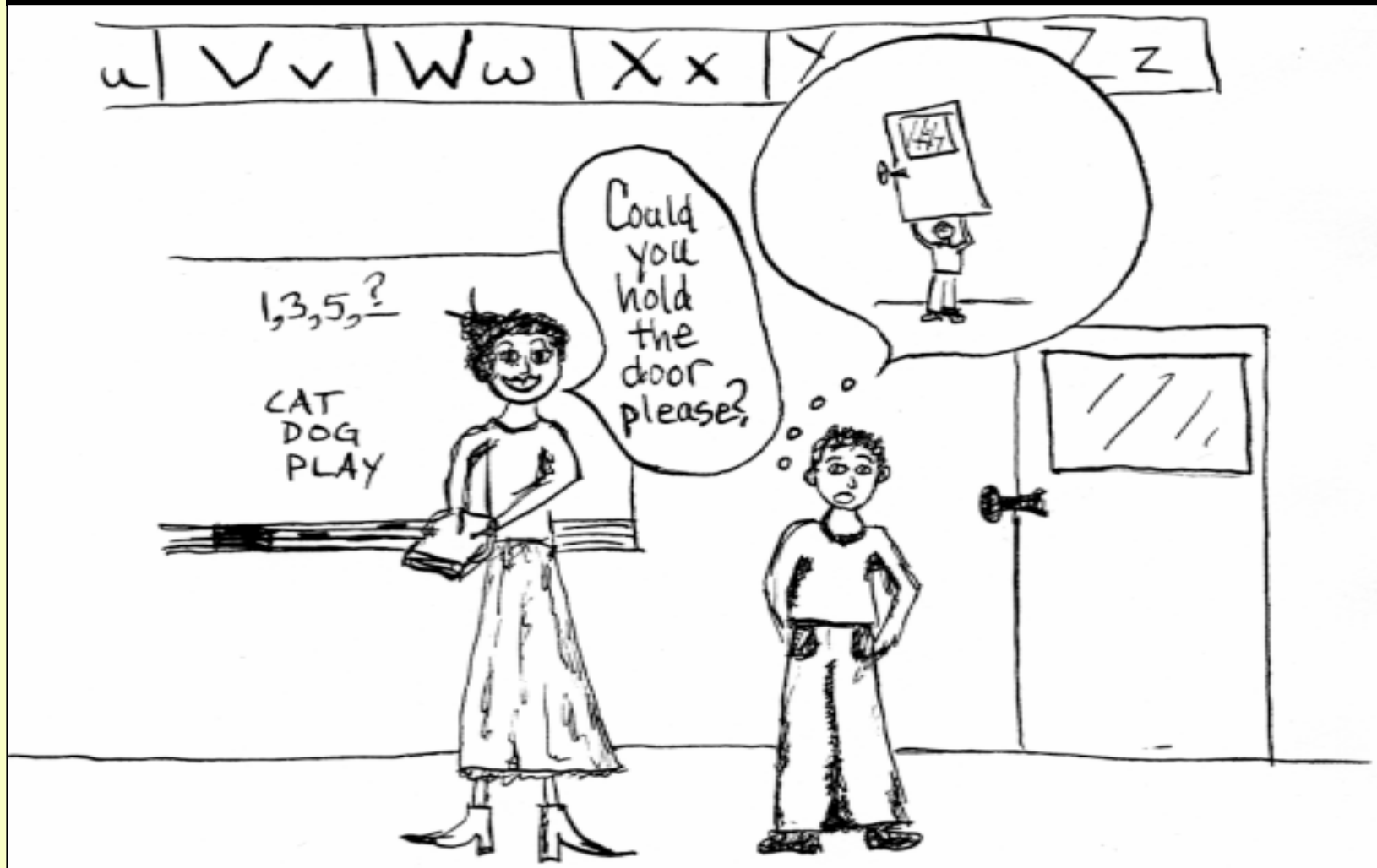
# THE HIDDEN CURRICULUM - LEGAL SYSTEM

Debbaubt, D. (2001). *Autism, Advocates, and Law Enforcement Professionals*

## Route 9 — Speed Limit 55

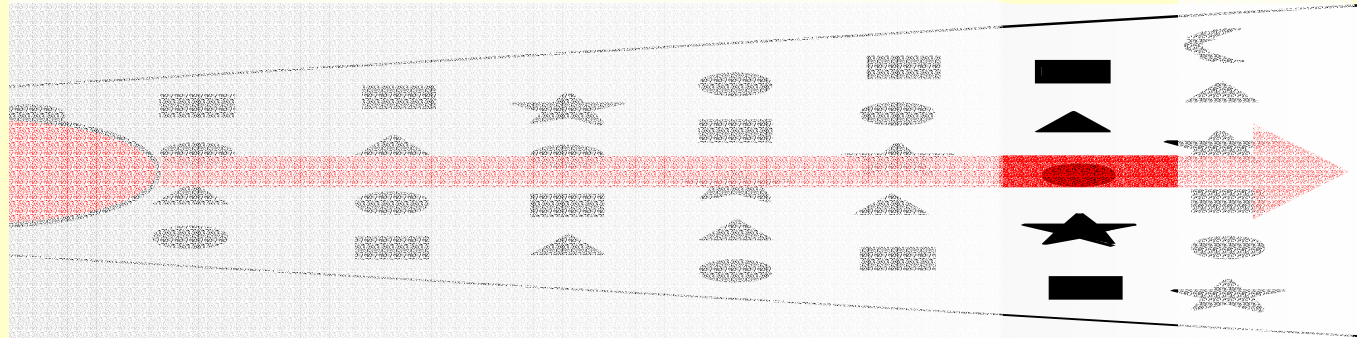


# HOLD THE DOOR PLEASE?



Laura Jekel, 12/2000

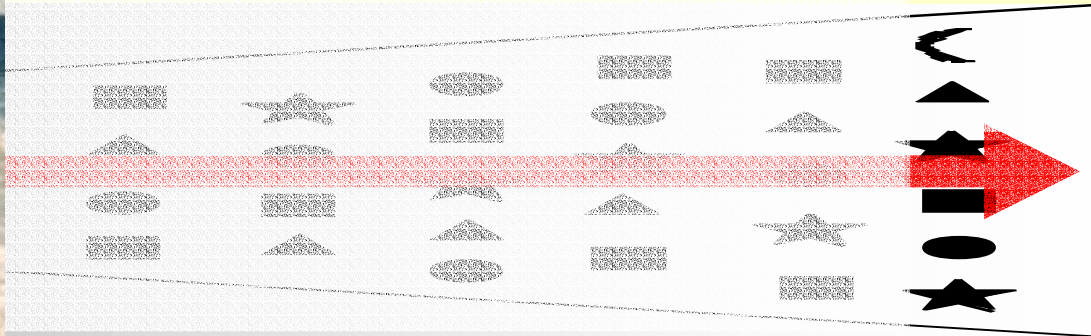
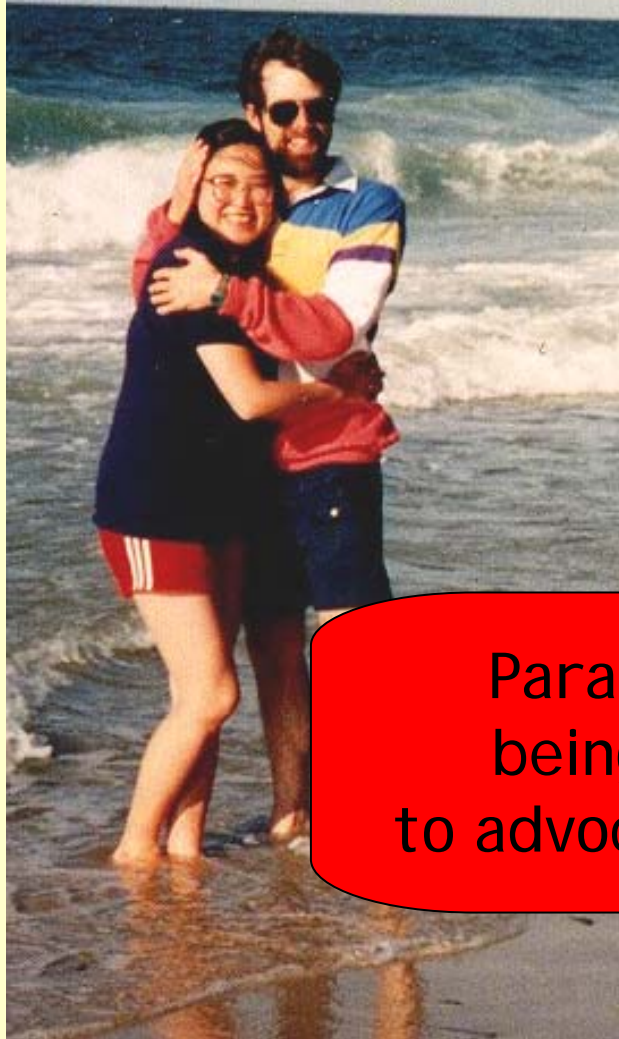
# A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 13



AGE	0	1.5	2.5	4	6	8	10	13	19
<b>E</b>	Typical development	Autism bomb hits	Putnam evaluation of atypical development, strong autistic tendencies & psychotic	Enter Putnam	Kindergarten	Cracking rocks	Concern about dropping the letter "e."	Middle and high school	Finally getting it together but still often in left field
<b>V</b>	Turn over at 8 days	Withdrawal from environment		Condition improves to "neurotic"	Social & academic difficulties	Special interests in astronomy and weather	My friend says "he feels like a pizza" and I argue with him that he does not look like a pizza and probably does not feel like one either		
<b>E</b>	Rapid physical and motor development	Tantrums		The wonderful world of	Discovered making a mess of	Teacher concerns for reading and		Discovering the band room	Time to focus more on people and not their bicycles
<b>N</b>									
<b>T</b>									
<b>S</b>									

**Interests, Relationships & Community**

# A CLOSER LOOK AT MY PLACEMENT ON THE AUTISM SPECTRUM — 19



	4	6	8	10	13	19
on cal me g	Enter Putnam	Kinder-garten	Cracking rocks	Concern about dropping	Middle and high school	College
	Condition improves to "normative"	Social & academic diff	Special	My friend "he	Finally getting it together but still often in left field	More friends
				"he	Discovering the band room	Dating
				and I	Time to focus more on people and not their bicycles	Others really do think differently
				with		Utopia!
				at he		
				ot		
				ke a		
				nd		
				ly		
				ot		
				feel like one either		
me	baby food	Yikes bikes!				

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

# **S E L F - A D V O C A C Y   D E F I N E D**

**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.**

# LIVING IN TODAY'S WORLD

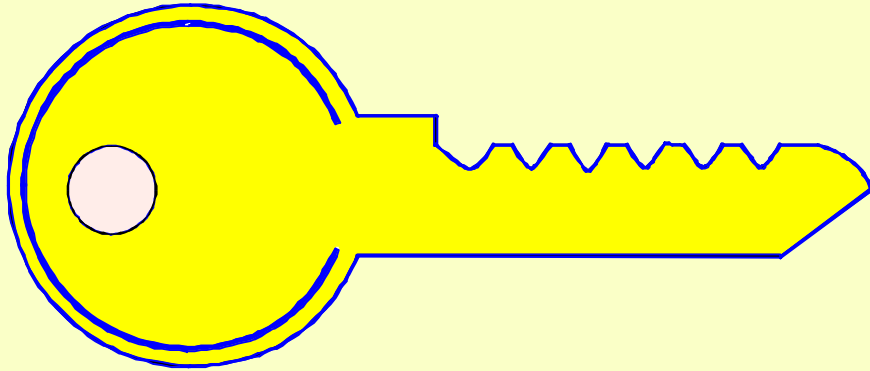
## REALITY CHECK

**Most people  
are busy with living**

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



# Making College Right



**MAJOR KEY** ———> **SUPPORT**

**Family**

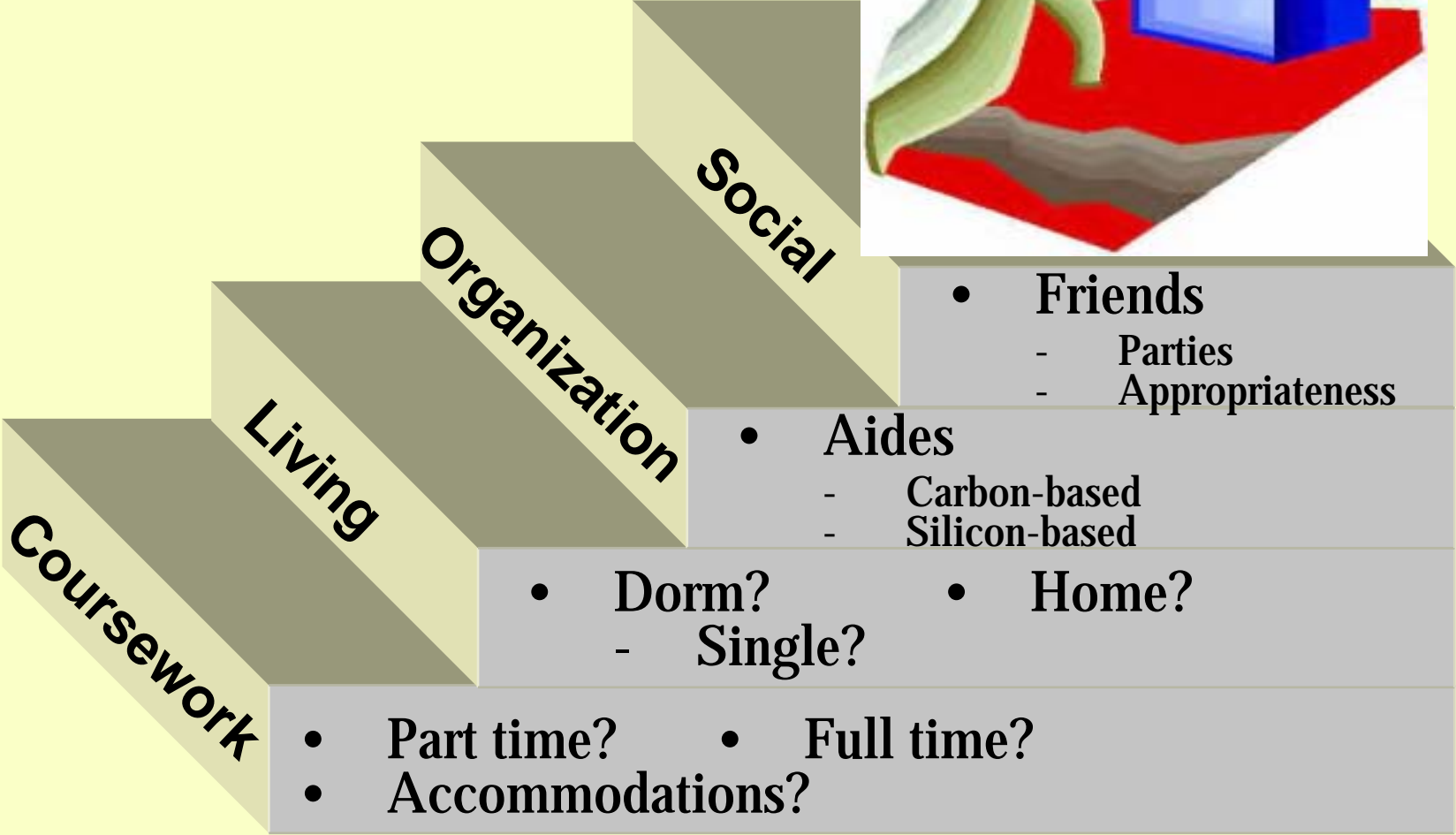
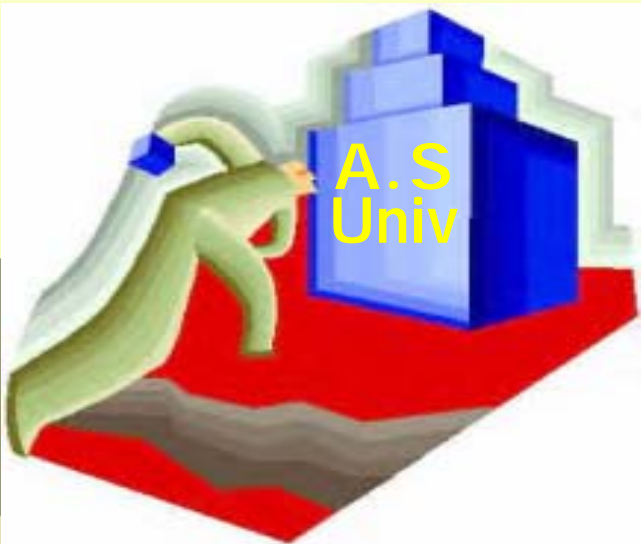
**Interconnection is Vital**

**Friends**

**School**

**Other**

# SOME STEPS FOR A SUCCESSFUL COLLEGE EXPERIENCE



# Making College Right (Cont.)

## ACCOMMODATIONS WORKSHEET

Name: Any Student School: Any State College

Counselor: Unnamed Somebody Date: August 15, 2007

Challenge	Cause	Suggested Accommodation
Taking tests with multiple questions per page.	Visually over stimulating, gets lost in all the words.	<ol style="list-style-type: none"> <li>1. Only one question per page.</li> <li>2. Two sheets of paper to cover distracting verbiage.</li> </ol>
Unable to concentrate under fluorescent lights.	Perception of 60Hz cycling due to visual sensitivity	Explore alternate lighting, sit next to window, wear baseball cap in class.
Scheduling long term assignments.	Poor executive function.	Regularly meet with professor (perhaps once a week) to keep on target with lengthy assignments.

**WHAT IS IT LIKE  
TO HAVE AUTISM?**

**Let us find out...**

# SPEAKING AS A COGNITIVE TASK

## Two kinds of tasks

1. Associative — Multi-tasking — Background
2. Cognitive — Singular — Foreground

Adapted from: Lavoie, R. (1989). *Understanding Learning Disabilities: How difficult can this be?* (Videotape) Greenwich, CT: Peter Rosen Productions.

# SPEAKING AS A COGNITIVE TASK

## **Associative — Multi-tasking — Background**

- Drive and talk
- Walk and chew gum
- Listen and take notes
- Talk and make eye contact
- Decode nonverbal cues

Adapted from: Lavoie, R. (1989). *Understanding Learning Disabilities: How difficult can this be?* (Videotape) Greenwich, CT: Peter Rosen Productions.

# **SPEAKING AS A COGNITIVE TASK**

## **Associative — Multi-tasking — Background**

**Now... Let's tell a story in a round-robin fashion**

**Instructions:**

**All you need to do is relate your sentence to the previous person's sentence.**

Adapted from: Lavoie, R. (1989). *Understanding Learning Disabilities: How difficult can this be?* (Videotape) Greenwich, CT: Peter Rosen Productions.

# SPEAKING AS A COGNITIVE TASK

## **Cognitive — Singular — Foreground**

- Driving for the first time
- Arithmetic in another language
- For many with autism:
  - Listen and take notes
  - Talk and make eye contact
  - Decode nonverbal cues

Adapted from: Lavoie, R. (1989). *Understanding Learning Disabilities: How difficult can this be?* (Videotape) Greenwich, CT: Peter Rosen Productions.



# SPEAKING AS A COGNITIVE TASK

## Cognitive — Singular — Foreground

**Now... Let's tell a story in a round-robin fashion again  
EXCEPT**

- This time... no words can contain the letter “n”
  - No “n” at the beginning, middle, or end

Adapted from: Lavoie, R. (1989). *Understanding Learning Disabilities: How difficult can this be?* (Videotape) Greenwich, CT: Peter Rosen Productions.

# Beyond the Wall

Personal Experiences with  
Autism and Asperger Syndrome

SECOND EDITION



スティーブン・ショア

Stephen Shore

森 由美子 [訳]

## 壁のむこうへ

自閉症の私の人生

Beyond the Wall

Personal Experiences with Autism and Asperger Syndrome  
(SECOND EDITION)

学研

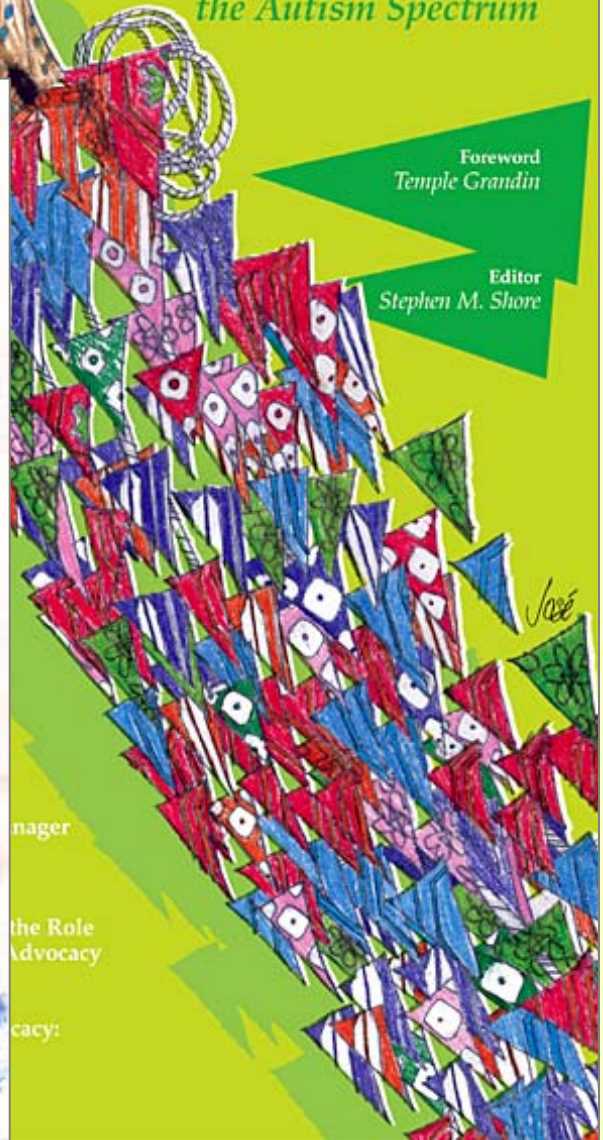


# Ask and Tell:

Self-Advocacy and Disclosure  
for People on  
the Autism Spectrum

Foreword  
Temple Grandin

Editor  
Stephen M. Shore



nager

the Role  
Advocacy

cacy: