

EFFECTIVE SELF-ADVOCACY

For People on the Autism Spectrum

(and for everyone else!!!)

PROMOTING LIFE-LONG STRATEGIES FOR SUCCESS

Tel Aviv

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SCAN

ADVOCATE

DISCLOSE

SCAN

ADVOCATE

DISCLOSE



ISRAEL



AREAS OF SELF-ADVOCACY

Overview

What we are doing now to prepare for successful self-advocacy?

Developing an Advocacy Plan

Awareness of Need

- Environmental
- Cognitive
- Social-Emotional

Advocacy Effort

Disclosure

Interdependent Living for

Education

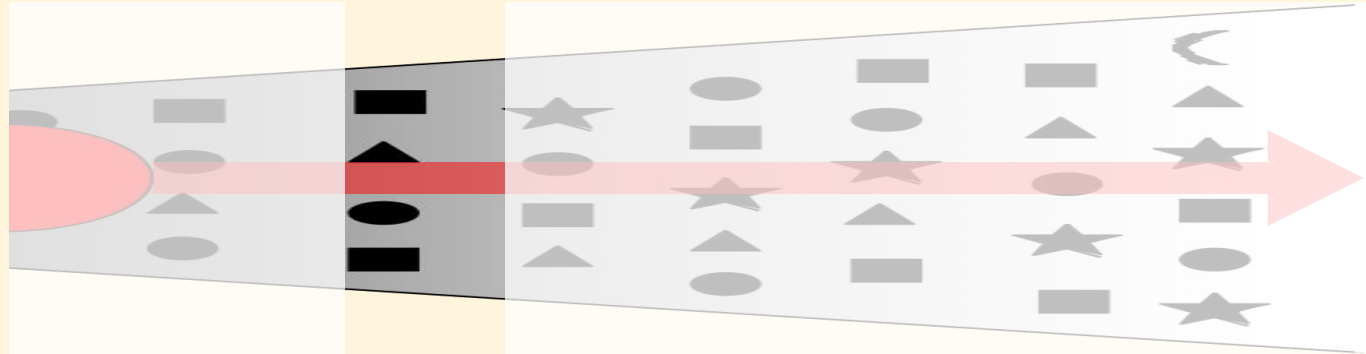
Community

Relationships

Residential

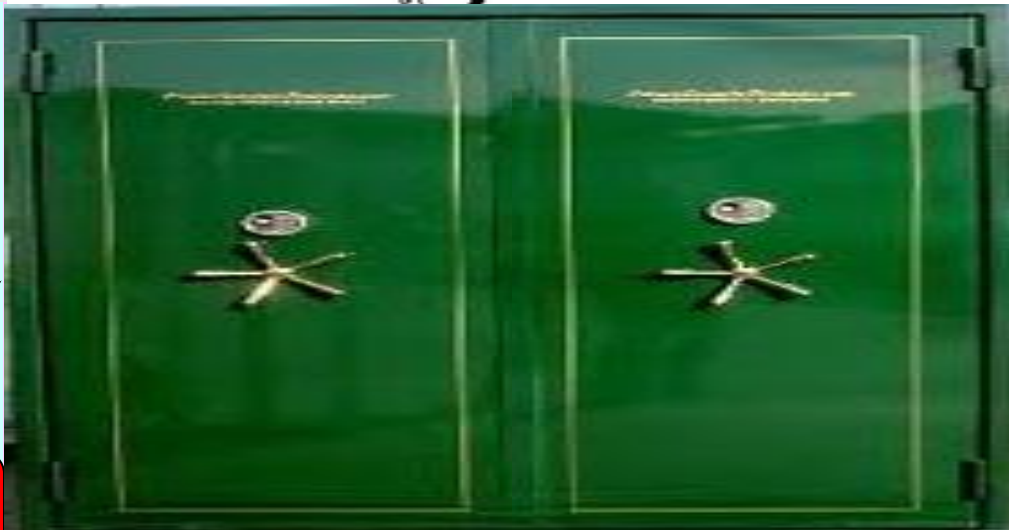
Employment

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, strong autistic tendencies & psychotic						
V	Turn over at 8 days	Withdrawal from environment	Early intervention from parents who refute recommendations from						
E	Rapid physical and motor development	Tantrums							
N									
T									
S									

Self Awareness



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

Set the Stage for Self-Determination

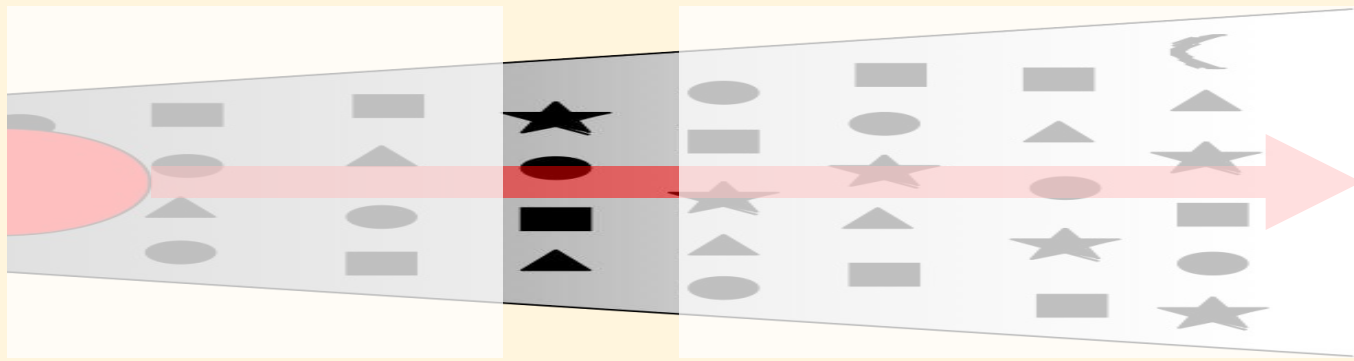
Acting as the primary casual agent in one's life and making choices and decisions regarding one's quality of life free from undue external influence or interference
(Wehmeyer, 1994).

Condition improves to “neurotic”
The wonderful world of watch motors

Self Awareness

Which Sets the Stage for **Disclosure...**

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



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

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?

FOUR STEPS TO DISCLOSURE

Self-Determination → Disclosure → Self-Advocacy

1. Awareness of strengths and challenges through verbal, pictorial, and other communication.

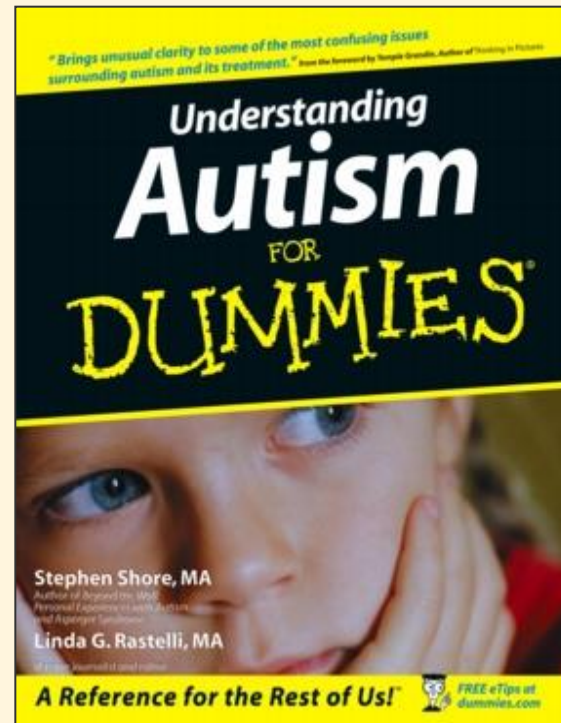
2. “Rack up” strengths and challenges.

3. Non-judgmental comparison of characteristic with others and potential role models.

4. Present the label summarizing a condition rather than a name for a set of deficits.



Making ones needs known in a way that others can understand and provide support.



FOUR STEPS TO DISCLOSURE

Planning for Disclosure

1. Awareness of strengths and challenges

3. Nonjudgmental comparison

2. "Rack up" strengths and challenges

Strengths	Challenges
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4. Present the label summarizing the condition

Disclosure – Telling a Person He has Asperger's

—Help Meaningfully Disclose to Ted he has Asperger's—

7 year old Ted has been asking why classmates make fun of him during recess, sees an occupational therapist weekly, takes an entire class period to copy just a few words from the board, and to explain his clumsiness during gym. You notice that over the last month Ted's questions have become more frequent.

Additionally, Ted no longer spends hours at the electronic keyboard where he's a master at composing music and has lost interest in using the computer in the living room over which you used to chase him away so he would do his homework, and generally seems listless.

Ted's teacher indicates he no longer helps his classmate Deb in mathematics in exchange for her assistance in creative writing. Somehow, Deb has the ability to help Ted organize his thoughts for creative writing assignments in a way no one else, including the paraprofessional, could.

You and your spouse decide now is the time to tell Ted he has Asperger Syndrome.

Help Ted's parents plan their disclosure to Ted that he has Asperger Syndrome, emphasizing his characteristics while honoring strengths using the 4 step disclosure process.

1. Strengths & Challenges
2. "Rack em up"
3. Nonjudgmental Comparison
4. Present the Label

**FINDING LIKES
AND DISLIKES AS A
KEY TO SELF-AWARENESS**

FINDING YOUR OWN SENSORY PREFERENCES

Likes & Dislikes

What types of sounds, tastes, smells, touches, and things you see do you like and make life **easier**?

What types of sounds, tastes, smells, touches, and things you see do you **dislike** and make life **harder**?

FINDING YOUR OWN COGNITIVE PREFERENCES

Likes & Dislikes

What types of things, subjects in school, or tasks at work do you find **easy** and **enjoyable** to do?

What types of things, subjects in school, or tasks at work do you find **difficult** to do and **dislike**?

FINDING YOUR OWN PREFERENCES

Likes & Dislikes

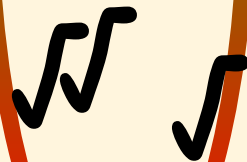
Strengths



Math

Gym

Read-
ing



Math

Gym

Read-
ing

Challenges



KEEPING IT STRONG

SELF-ADVOCACY

You're Lost... And you ask someone for directions...

“After the 6th light you look for the big tree on the left and take the third right. Then after the second church you see a fire station and go left. After going left you take a right at Tom Street. Drive for 4 blocks and keep bearing right until you see a stream on left which tells you to take a bridge on the right headed towards the water tower. When you pass the water tower take the second left and pull into a parking space in front of International Bicycle Shop and you are there!

Wow!!! Too much to remember!
What are you going to do?

1. You suddenly realize there's way too much information for you to remember

2. Hold on a moment! Can you wait a moment while I get something to take this down?

3. I won't remember it all!
Thanks for waiting...

SCANNED

ADVOCATED

DISCLOSED

SELF-ADVOCACY FOR PEOPLE WITH AUTISM

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.

DEVELOPING A SELF-ADVOCACY PLAN

SIX STAGES TO SELF-ADVOCACY

1. **Planning and Modeling:** After involvement with the planning for their own self-advocacy, the person observes the partner engage in the act of advocating.
2. **Facilitation and Confidence Building:** Facilitator serves as a guide for the self-advocacy process and remains ready to step in as needed.
3. **Partnering and Letter Writing:** Equal sharing of advocacy responsibilities. Advocate takes the lead as facilitator offers strong guidance, moral support while the person does most of the advocating. Letter writing.

Adapted from Sibley, K. "Help me help myself." in Stephen Shore (ed.).
Ask and tell: Self-advocacy and disclosure for people on the autism spectrum. Shawnee Mission, KS: Autism Asperger Publishing Company, P.
35.

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.

35.
Adapted from Sibley, K. "Help me help myself." in Stephen Shore (ed.).
Ask and tell: Self-advocacy and disclosure for people on the autism spectrum. Shawnee Mission, KS: Autism Asperger Publishing Company, P.

Helping a Samantha Advocate for Herself - Case Study

—Three-Step Process for Effective Self-Advocacy—

A 10-year old student in an inclusive classroom, Samantha has been coming home crying for the past week. Through discussion with Samantha and classroom observation you see that some of students take great fun in watching Samantha squirm as they lightly touch her in apparent hope that Samantha will eventually strike out... and get blamed for starting a fight.

Previously, you would have intervened by talking with Samantha's homeroom teacher about how others are taking advantage of her tactile hypersensitivity.

As part of Samantha's team you realize that it is time to work on self-advocacy.

Choose one of the six stages of self advocacy...

- 1.Planning and modeling
- 2.Facilitation and confidence building
- 3.Partnering and letter writing
- 4.Moral support
- 5.Taking the lead
- 6.Independent self-advocacy

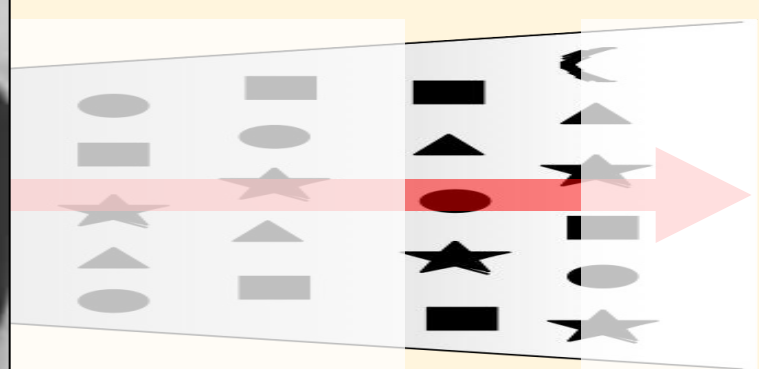


Three-Step Process for Self-Advocacy

Build the foundation —> Awareness

1. **Scan** Sensory issues
2. **Advocacy plan** Inform another of one's needs in a way they can provide support
3. **Disclosure** The reason why

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



	8	10	13	19
N				
T				
S				
	Cracking rocks	Concern about dropping the letter "e."	Middle and high school	
	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	
	Teacher concerns for reading and		Discovering the band room	
			Time to focus more on people and not their bicycles	

Interests, Relationships & Community

MY ADVOCACY PLAN

Name _____

SCAN: Where is the challenge?

1. Sensory
2. Cognitive
3. Socio-emotional

Perception of the environment

How we think

Social cues and how we feel

ADVOCACY:

Explaining your needs

DISCLOSURE:

Giving the reason why

SCAN

Challenge

What is causing the difficulty?

ADVOCACY

Explaining your needs

...promoting greater understanding and in a way the other can provide assistance

DISCLOSURE

The reason

Partial – Note specific characteristic affecting a situation only

Full – Diagnosis

MY ADVOCACY PLAN

Name _____

SCAN

Challenge

Sensory

Fluorescent lights

Cognitive

Remembering verbal instruction

Socio-emotional

Decoding jokes

ADVOCACY

Explaining your needs

Ask instructor to change lighting

Request instructor for written instructions

Ask for fellow students to tell you when they make a joke

DISCLOSURE

The reason

Partial – I have sensitive eyes

Partial – I remember things better when I write them down

Partial – I take things very literally

Helping Ellen Advocate for Herself - Case Study

—Developing an Advocacy Plan for Effective Studying—

Having just been awarded a study carrel of her own, 18-year old Ellen is very happy of her space away from the distracting open seating of the library lobby. Upon unlocking the door to her carrel for the first time she quickly realizes that productive work will be impossible for her due to her fluorescent light sensitivity.

To this point, no one at the university knows Ellen has Asperger Syndrome; and with it a sensitivity to fluorescent lights.

As Ellen's friend you realize that it is time for her develop an advocacy plan.

Please help Ellen work through and develop a three-step advocacy plan .

1. **SCAN** —————> Find the challenge

- **Sensory** Perception of environment
- **Cognitive** Thinking style
- **Socio-Emotional** Social cues & how we feel

1. **ADVOCACY** —> Explain your needs Mutual understanding/trust

2. **DISCLOSURE** -> The reason why Partial or full

THE ADULT YEARS

Disclosure – Telling another one has autism

—Help George plan how to tell another he has autism—

The best teller in the bank, George never uses a calculator and has cashed out to the penny for the past 15 months. He is also the first to help others having difficulties balancing their books, much to his coworkers' gratitude – especially to Jane who is the bank's star person to go to when there is a customer dispute.

However George has dozens of notes stuck chaotically all over teller window and workspace. Conversations with his supervisor about an orderly workspace result in George indicating the necessity of these notes for remembering complicated bank procedures. Given his great efficiency and good nature, the branch supervisor leaves George to his work, albeit mystified.

A manager from corporate headquarters is coming next week. As a result, the supervisor has asked George to make an appointment with him to discuss the necessity of a clean, organized work space.

Until now, George has never felt a need to disclose having autism to anyone. Given the recent turn of events, George now realizes perhaps this time has come.

Help George...

1. understand his needs using the 4 stages of self-disclosure, and,
2. The 3 step model for self-advocacy.

Self-Disclosure Process

1. Strengths & challenges,
2. “rack em up”,
3. nonjudgmental comparison,
4. present the label,
and...., or...
5. develop an advocacy plan

Self-Advocacy

1. Scanning
3. Disclosure
a. full
b. partial

The House of Self-Advocacy



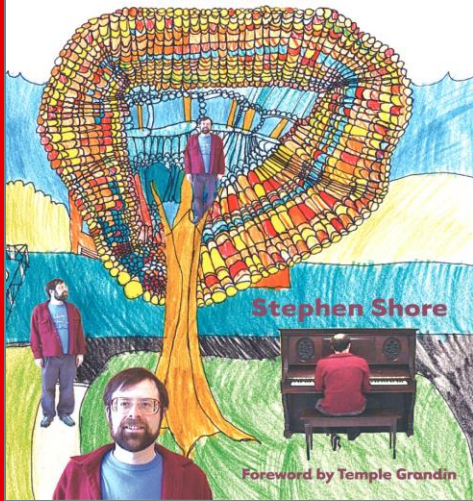
TURNING AWAY FROM CLOSED DOORS TO OPEN ONES

Defining Success



Beyond the Wall

Personal Experiences with
Autism and Asperger Syndrome
SECOND EDITION



Stephen Shore

Foreword by Temple Grandin

破牆而出

我與自閉症、亞斯伯格症共處的日子

著者：史帝芬·蕭爾 (Stephen Shore)
譯者：丁凡

這座牆是沒有牆或與世界的隔牆；
相反的，我努力突破自我障礙，終於可以與社會零一切。
這期間在自我探索的旅程，生命還經歷驚人的成長。
這種狂熱的旅程，讓我對上獲得與對的成長
發展出另一種存在……

Beyond the Wall
personal experiences with autism and Asperger syndrome

スティーブ・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

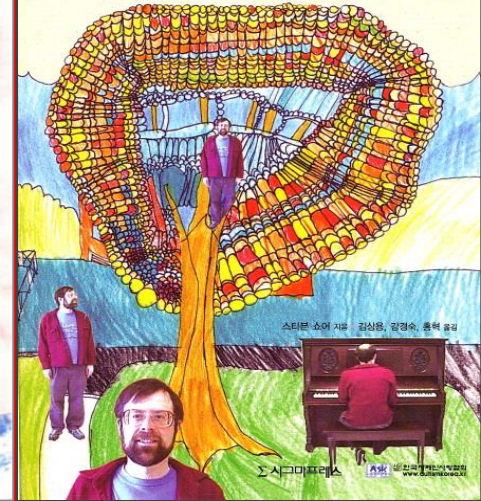
Personal Experiences with Autism and Asperger Syndrome

(SECOND EDITION)

[学研]

벽을 넘어서

행복을 찾은 어느 자폐인의 이야기



스티븐 쇼어 지음 김성용, 김경숙, 홍희 옮김

시공아카데미

www.autismasperger.net

Ask and Tell:

Self-Advocacy and Disclosure
for People on the Autism Spectrum



Communicating Through Advocacy and Self-Disclosure: Four Ways to Connect Ruth Dalton Jordan-Harris

Help Me Help Myself: Finding and Learning Kristina Shteyn

Using the IEP to Build Skills in Self-Advocacy and Disclosure Stephen M. Shore

When Your Own Case Manager Roger N. Meyer

Building Alliances: Community Identity and the Role of Allies in Adult Self-Advocacy Phil Schwartz

Disclosure and Self-Advocacy: An Open Door Policy Lisa Holiday Willey

"Brings unusual clarity to some of the most confusing issues surrounding autism and its treatment." - from the foreword by Temple Grandin, Author of *Thinking in Pictures*

Understanding Autism FOR DUMMIES



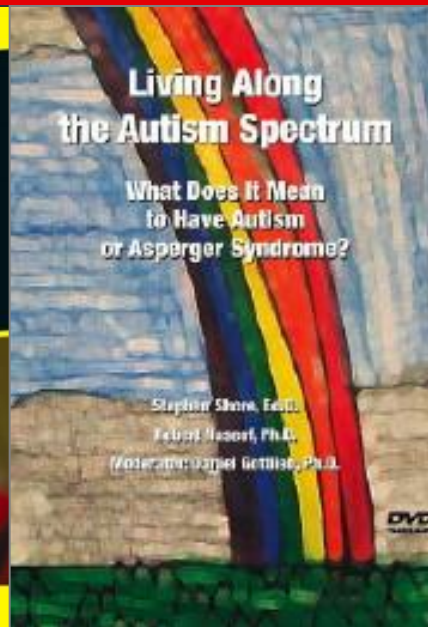
Stephen Shore, MA
Author of *Beyond the Wall: Personal Experiences with Autism and Asperger Syndrome*

Linda G. Rastelli, MA

A Reference for the Rest of Us! FREE eTips at dummies.com

Living Along the Autism Spectrum

What Does It Mean to Have Autism or Asperger Syndrome?



Stephen Shore, Ed.D.
Felicia Jacob, Ph.D.
Katherine Daniel, Ph.D.

Ask and Tell: Self-Advocacy and Disclosure for People on the Autism Spectrum

自閉症スペクトラム 生き方ガイド

自己権利擁護と障害表明のすすめ

スティーブ・ショア 著 森由美子 訳 荒木穂積 監訳



own case manager
community identity
getting along

クイズ
お楽しみ