



A Plea for Practical Supports

One Autistic's Need for a Person-Centered Model of Care

NM-LEND 2020-2021 | CAPSTONE PROJECT

J. ALEXANDER DOUGLAS

LEND Competencies

❖ Competency 1: Family-Centered Practice

- ◆ 1.5: Demonstrate and respond to the impact of disability on family
- ◆ 1.9: Identify **family-centered practices** in the community and services systems

❖ Competency 2: Interdisciplinary Practice

- ◆ 2.8: Demonstrate skills in ASD/NDD **evidence-based intervention**

❖ Competency 3: Knowledge, Skills and Attitudes

- ◆ 3.4: Describe MCH-population **health disparities** and offer **strategies** to address them

A blurred background image of a desk setup. In the foreground, a pair of dark-rimmed glasses rests on a white surface. Behind the glasses, a laptop keyboard is visible. To the right, a pen lies on the desk. The overall scene is softly lit and out of focus, creating a professional and academic atmosphere.

Introduction

CASE STUDY (It's me. I'm the Case Study)

|Introduction| • Problem-Framing • Research • Product • What Next? • Dissemination

My Story

- ❖ Autism misdiagnosed from childhood forward as behavioral health disorder(s)
- ❖ I've been in-and-out of behavioral health counseling, since age 6!
- ❖ I have been only marginally successful living alone
 - ◆ (...and completely **UN**-successful living with roommates)
- ❖ In 2014, I experienced homelessness
- ❖ Earnings Projection for 2021 = \$3,700*
 - ◆ (up from \$1,263* in 2019)



*before government subsidy and financial assistance

Poverty is the Symptom of Ineffectiveness

When this is true:

- ❖ Plenty of work is available
 - ◆ My business network includes 900+ colleagues, friends, and fans of my work
- ❖ I hold a diverse skillset
- ❖ I'm experienced
- ❖ I'm motivated

Why does this still happen?

- ❖ I am quickly fired or asked to resign
 - ◆ Often citing 'cost effectiveness' or being a poor 'match' to the position / company culture
- ❖ I must withdraw from 50% of my freelance contracts
 - ◆ Because my contribution falls short of the expected output



Problem-Framing

WHAT'S REALLY GOING ON, HERE?

Introduction • [|Problem-Framing|](#) • Research • Product • What Next? • Dissemination

Three Areas of Struggle

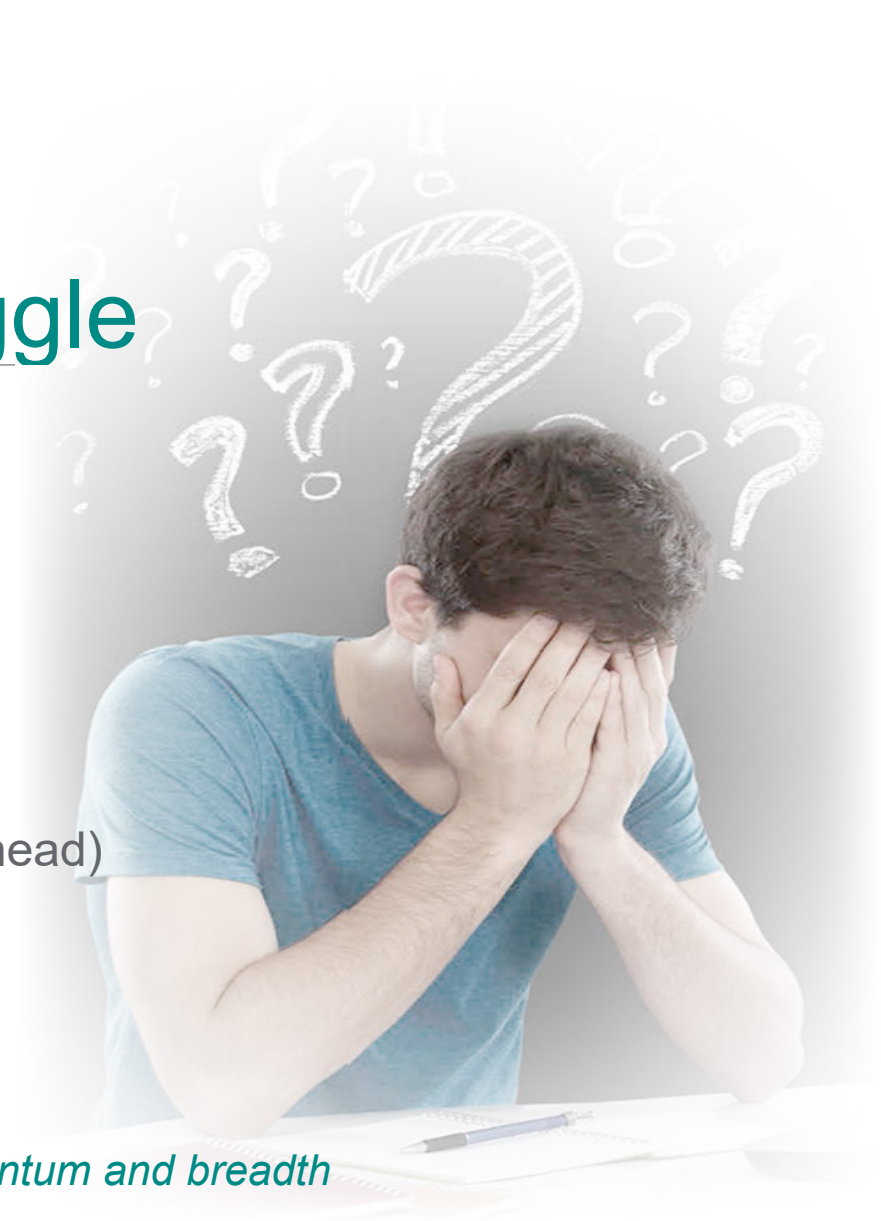
Let's break down the actual problem:

❖ My 3 major areas of struggle include...

- ◆ Neuro-Social Communication Patterns
(what I say and how I say it)
- ◆ Executive Functioning Differences
(how quickly and how well I organize info in my head)
- ◆ Sensory Processing / Sensory Integration
(tolerance for external + internal stimuli)

...At the root of all 3 is hyper-awareness!

Hyper-awareness adds detail and depth ... but it can steal momentum and breadth



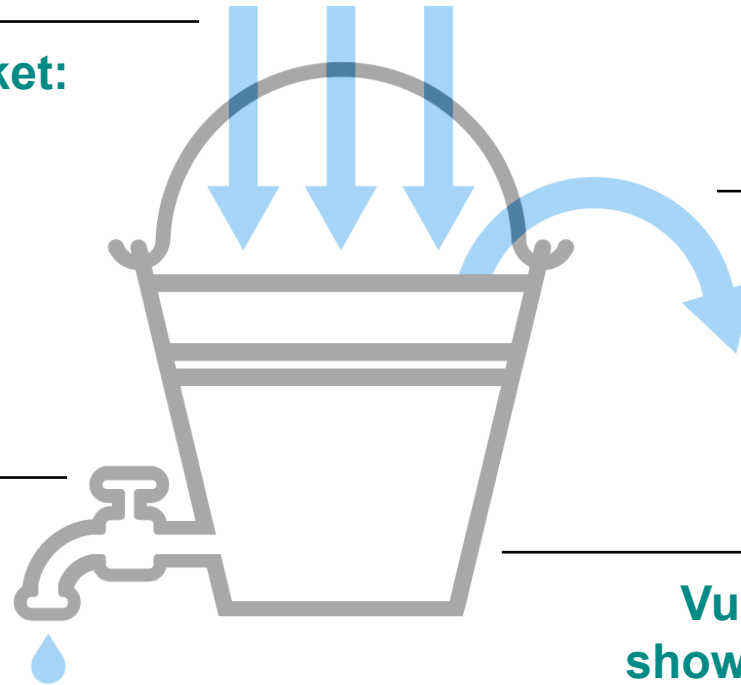
Autistic The ^ Stress Bucket Model

Stress flows into your bucket:

Sensory Inputs
Memory / Cognition
Executive Functioning Tasks
Anxiety / Impulsivity
Hunger / Nutrition

Coping skills open the tap:

Wide tap = stress drains out rapidly
Narrow tap = bucket fills faster



Overflow =

Meltdown
Panic Attack
Sensory Intolerance
Going Nonverbal
Delayed Cognition
Brain Fog

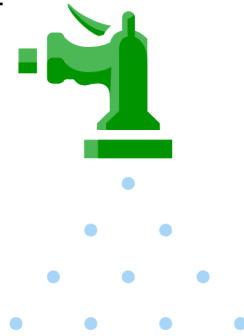
Vulnerability (typically)
shown by size of bucket

(adapted from Brabban and Turkington, 2002)

UNSW worksheet: <https://student.unsw.edu.au/sites/all/files/uploads/CAPS/Stress%20Bucket.pdf>

Which Fills Faster?

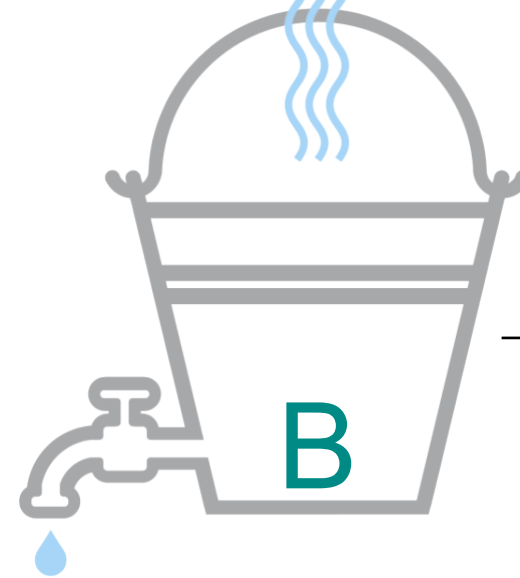
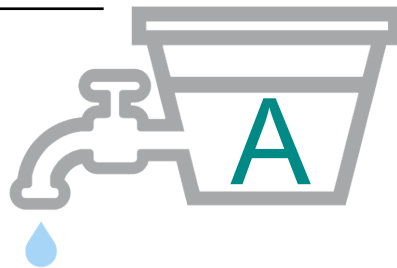
Garden Hose =
40 L / min



Fire Hose =
1,000 L / min



1x =
neuronormative
bucket



?x =
Autistic bucket

(assume equal tap function)

Neo Gains 'The Sight'

~ from *The Matrix* (1999, Warner Bros.)



The lens of Autism—not just offers, but—**DEMANDS** hyper-awareness of details others often miss.
While viewing the world through its 'Source Code', one must learn to filter out
extraneous sensory data, for ease of navigation and communication.

Case Summary

Big Takeaways:

1. Talk Therapy is **NOT** Enough
2. Poverty = Symptom of Ineffectiveness
3. 3 Major Areas of Struggle =
 - ◆ Neuro-Social Communication Patterns
 - ◆ Executive Functioning Differences
 - ◆ Sensory Processing / Sensory Integration
5. Bucket Overflow \neq Small Bucket Size
6. Hyper-Awareness =
 - ◆ Drinking 'From the Fire Hose'
 - ◆ Noticing What Others Miss
 - ◆ Filtering the 'Source Code' of Life'



Research

Introduction • Problem-Framing • **|Research|** • Product • What Next? • Dissemination

More Research is Needed

Detailed Literature Review
+ Additional Research May:

- ◆ Confirm prevalence
- ◆ Inform best-practice

That said, common-sense strategies are still useful!



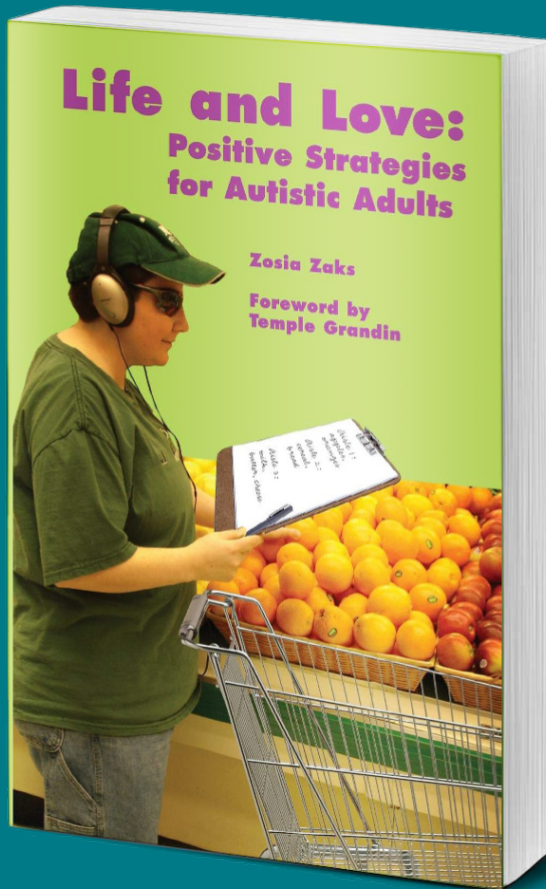
image source: http://www.seppo.net/cartoons/albums/cartoons/environment/climate/climate_research_actions_eng.jpg

Coping Ahead of Time, Toward Difficult Situations

1. **Describe** a situation that is likely to create a sensory emergency.
2. **Decide** what coping or problem-solving skills you want to use, for this.
3. **Imagine** the situation in your mind as vividly as possible.
4. **Rehearse** coping effectively with the situation.
5. **Practice** relaxation *after* rehearsing.

(adapted from Linehan, 2015)

An Inspired Idea!



Zosia Zaks, on Sensory Emergency Kits:

"Everywhere I go, I carry a [SEm-Kit].

This kit contains the items I need to handle a sensory emergency should one arise. Most items fit in my jacket pockets—even the walkman I use to drown out unpleasant noises. You can also carry your items in a special backpack or in your purse.

Everyone's [SEm-Kit] will be different. Think about your senses, what bothers you, and how you could cope."

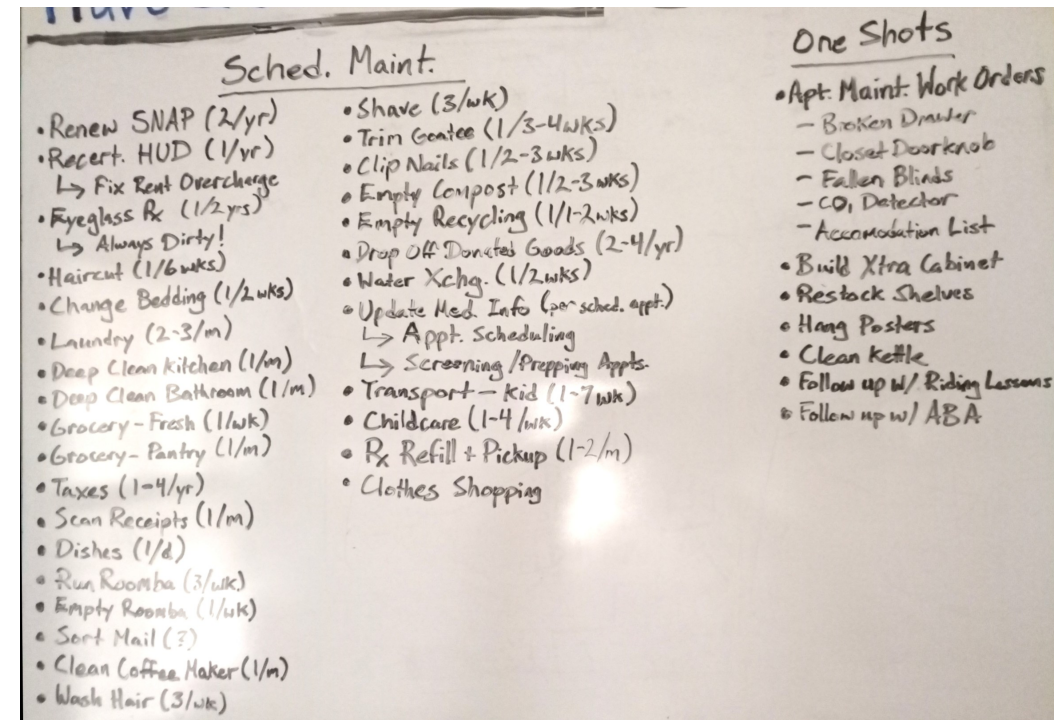
(Zaks, 2006)

Needs Inventory

❖ 45 Areas of Need Identified

- ◆ 34 Recurring Needs
(Scheduled Maintenance)
- ◆ 11 Transitory Needs
(One Shots)

A longterm strategy must be both comprehensive + robust!



Automation + Task Offloading



image source:

<https://store.irobot.com/default/roomba-vacuuming-robot-vacuum-irobot-roomba-690/R690020.html>



 elliegrid

image source:

<https://elliegrid.com/products/ellie-smart-pill-box>

Research Summary

Big Takeaways:

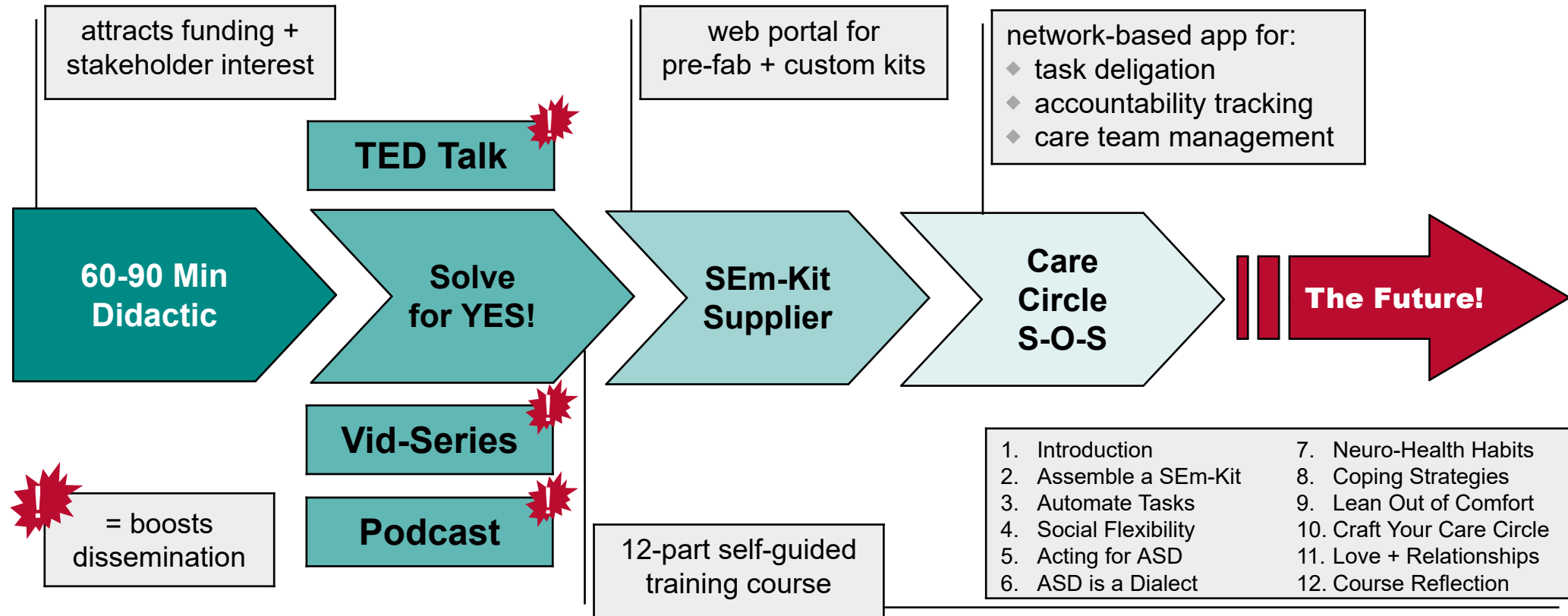
1. More Research is Still Needed
...so, for now...
2. Practice “Coping Ahead”
3. Carry a SEm-Kit
(Sensory Emergency Kit)
4. Automate Tasks Using Tech
5. Build Strategies to Offload Tasks
5. Seek Longterm Strategies That Are:
 - ◆ Comprehensive
 - ◆ Robust

A photograph of a computer setup made entirely of cardboard boxes. A large box serves as the monitor, sitting on a smaller box base. In front of it is a keyboard box, and to the right is a mouse box connected by a cord. The setup is on a light-colored wooden desk.

Product

Introduction • Problem-Framing • Research • **|Product|** • What Next? • Dissemination

Info-Product Development Chain





What Next?

Introduction • Problem-Framing • Research • [|What's Next?|](#) • Dissemination

Next Steps

1. Meet with CDD constituents to discuss proposed marketing plan for didactic.
2. Work with a multidisciplinary care team (including BCBAs and SLPs) to brainstorm, implement, and revise person-centered practical support strategies.
3. Conduct a thorough literature review to determine what data—if any—has already been collected on the use of person-centered practical supports, and—if applicable—best practice, regarding which interventions work most effectively for those with sensory processing differences.
4. Put a Research and Development team together to develop, refine, and standardize the S-O-S.
5. Investigate emerging technology—particularly ‘convenience items’ (like Roomba and Elliegrid)—to evaluate their potential as home health aids, especially as relates to improving personal effectiveness for those who identify as neurodivergent.
6. Consult with educators experienced in developing academic curriculum, to advise best practice in adapting ideas and strategies into coursework.



Dissemination

Introduction • Problem-Framing • Research • Product • What Next? • **|Dissemination|**

Plan for Dissemination

1. Present **Didactic** to known + prospective stakeholders.
2. Rewrite didactic to fit **TED Talk** format.
3. Expand topical material into '**Solve for YES!**' self-guided training.
4. Promote material through **Guest Appearances** on YouTube, podcasts, etc.
5. Partner w/ an online vendor to provide **SEm-Kit** order fulfillment.
6. Re-brand or repurpose existing software architecture into **Care Circle S-O-S** platform.

References

American Red Cross Standard First Aid Workbook. (1988). The American Red Cross.

Birkby, R. C. *Boy Scout Handbook.* (10th ed.) (1990). Boy Scouts of America.

Dialectical Behavior Therapy for Adolescents and Families. (2014). Awake and Aware.

Linehan, M. M. *DBT Skills Training and Worksheets.* (2nd ed.) (2015). Guilford Press.

Seton, E. T., & Baden-Powell, R. S. S. *The Boy Scouts Original 1910 Handbook: The Early-Version Temporary Manual For Use During The First Year Of The Boy Scouts.* (Legacy ed.) (1910-2019). Doublebit Press.

Wilde, O. *An Ideal Husband.* (5th ed.) (1912). Methuen & Co. Ltd.

Zaks, Z. *Life and Love: Positive Strategies for Austistic Adults* (1st ed.) (2006). Autism Asperger Publishing Co.



Questions?

