

**PART 1: Evidence-Based
Treatment for Toddlers with ASD:
What We Know Now and New
Research Directions**

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**What are the Active Ingredients
of Treatment?**

**What do we think makes a
treatment for ASD work?**

- Early is better.
- Individualized goals.
- Target core deficits and strengths.
- Monitor progress and flexibility in approach (3 months).

Other possible ingredients




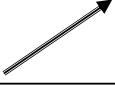
- Intensity matters (25 hours a week to mirror school; how much for younger kids?)
- Active engagement
- Low student/teacher ratio
- Family participation

Children with ASD do not participate as much or as happily in ordinary activities without support and structure.

Research tells us that...

...a variety of intervention strategies work well with **SOME** children with ASD.

Research tells us that a variety of intervention strategies work well with some children with ASD

		(NRC, 2001) Developmental/ Social- Pragmatic
	Contemporary Behavioral/ Naturalistic	
Traditional Behavioral/ Discrete Trial		

Evaluating the Level of Evidence

- I. True experimental group treatment designs (RCTs)
- II. Pre and post group treatment and multiple baseline designs
- III. Single-case experimental treatment designs (A-B-A)
- IV. Case-control cross-sectional or longitudinal descriptive group research designs
- V. Anecdotal reports of change in response to treatment.

Guiding Principles of Developmental Approaches to Intervention for Young Children with ASD

- Developmental framework
- Focus on the core deficits associated with autism
- Family-guided approach
- Natural environments
- Naturalistic teaching strategies

Wetherby & Woods, 2008

**What is the Evidence Base for
Developmental Interventions for Young
Children with ASD?**

III. Single-subject experimental designs

	N	Age	1.	2.	3.	4.	5.
Hancock & Kaiser (2002)	4	35-54	✓	✓			✓
Hwang & Hughes (2000)	3	32-43	✓	✓			✓
Ingersoll et al. (2005)	3	32-46	✓	✓			✓
Kaiser et al. (2006)	6	35-54	✓	✓	✓		✓
Kashinath et al. (2006)	5	33-65	✓	✓	✓	✓	✓

1. Developmental Frame; 2. Core Deficits; 3. Family Guided;
4. Natural Environment; 5. Natural Teaching Strategies

Wetherby & Woods, 2008

**What is the Evidence Base for
Developmental Interventions for Young
Children with ASD?**

II. Quasi-experimental group designs

	N	Age	1.	2.	3.	4.	5.
Boutware et al. (2006)	8	25	✓	✓	✓	✓	✓
Mahoney & Perales (2005)	20	32	✓	✓	✓		✓
McGee, morrier & Daly (1999)	28	29	✓	✓	✓	✓	✓
Rogers & DiLalla (1991)	49	46	✓	✓			✓
Wetherby & Woods (2006)	17	18	✓	✓	✓	✓	✓

1. Developmental Frame; 2. Core Deficits; 3. Family Guided;
4. Natural Environment; 5. Natural Teaching Strategies

Wetherby & Woods, 2008

**What is the Evidence Base for
Developmental Interventions for Young
Children with ASD?**

I. True experimental group designs

	N	Age	1.	2.	3.	4.	5.
Aldred, Green, & Adams (2004)	14	48	✓	✓	✓	✓	✓
Drew et al. (2002)	12	23	✓	✓	✓	✓	✓
Kasari, Freeman & Paparella (2006)	41	43	✓	✓			✓
McConachie et al. (2005)	26	38		✓	✓	✓	✓
Yoder & Stone (2006)	36	31	✓	✓			✓

1. Developmental Frame; 2. Core Deficits; 3. Family Guided;
4. Natural Environment; 5. Natural Teaching Strategies

Wetherby & Woods, 2008

Early Social Interaction Project

Model Demonstration & Research Project
funded by the U.S. DOE

Amy Wetherby & Juliann Woods
Project Co-Directors

esi.fsu.edu

SCERTS Intervention Model

Barry Prizant, Amy Wetherby, Emily Rubin, & Amy Laurent

- S- SOCIAL
- C- COMMUNICATION
- E- EMOTIONAL
- R- REGULATION
- T- TRANSACTIONAL
- S- SUPPORT

www.scerts.com

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Quasi-experimental Group Design Research Questions

1. Were there **within-group** differences in social communication measures on the CSBS from pre- to post-intervention for 18 toddlers who entered ESI in the 2nd year of life and participated in ESI for a year?
2. Were there **across-group** differences in social communication measures on the CSBS at post-intervention for 18 children with ASD who participated in ESI in the 2nd year of life and a contrast group of children who entered the early intervention system in the 3rd year of life?

Wetherby & Woods, 2006

Early Social Interaction Project

Collaborative Experimental Treatment Study
funded by Autism Speaks and NIMH

Florida State University
PI- Amy Wetherby

University of Michigan
PI- Catherine Lord

esi.fsu.edu

True Experimental Group Design

Randomized control trial with 96 parent-child dyads over 6 years beginning when child with ASD is 18 months

Crossover design comparing two parent-implemented 9-month interventions, 3 individual sessions per week (high intensity) and 1 group session per week (low intensity)

Child outcome measures include social communication and autism symptoms measured bimonthly and developmental level and adaptive behavior measured at pretest, crossover, and posttest

Measures of active engagement from monthly fidelity videotapes to measure the parent-child dyad

Research Aims

- **Aim 1. Intensity of Treatment:** To compare the effectiveness of high and low intensity condition beginning at 18 months of age on outcome measures from 18 to 27 months.
- **Aim 2. Timing of Treatment:** To compare the effectiveness of the high intensity condition beginning at 18 months of age with that beginning at 27 months of age on outcome measures.
- **Aim 3. Mediator of Treatment:** To determine whether parent synchronization is a mediator of response to intervention.
- **Aim 4. Moderator of Treatment:** To identify individual child and family characteristics which predict response to intervention.

ESI Adult Instructional Strategies

- Direct Teaching
- Guided Practice with Feedback
- Caregiver Practice with Feedback
- Video Feedback
- Modeling/Demonstrating
- Problem Solving
- Observing
- Conversations and Information Sharing

Intensity matters...

...so how do we achieve 25 hours per week in which the child is engaged **actively** and **productively** in meaningful activities?

(National Research Council, 2001)

Possible Mediating Variable: Active engagement

- A child is focused but can shift attention and problem solve, can communicate effectively, and benefit from learning opportunities in his/her environment.
- Coincides with demands of the social and physical environment.

(Prizant, Wetherby, Rubin, Laurent, & Rydell, 2006)

Operationalizing Active engagement

Is the child...

- actively participating in a productive activity
- well regulated
- engaging in reciprocal social interaction
 - > orienting to social stimuli
 - > shifting gaze to face
 - > responding to verbal bids for interaction
 - > initiating communication

Does the parent...

- provide *learning supports* to structure activities
- provide *interpersonal supports* to
 - > ensure comprehension
 - > synchronize with child's focus of attention
 - > maintain a balance of turns
- adjust expectations and demands based on child's emotional regulation

Video Vignette: Tyrone

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Hand washing- Before

Video Vignette: Tyrone

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Hand washing- After

ESI Activity Categories

<p>Play with Toys Blocks, Puzzles, Sand box, Playdough, Cars and Trucks, Ball Games, Baby Dolls</p>	<p>Play with People Social Games like Peek-a-boo, Rough and Tumble, Songs & Rhymes</p>
<p>Meals and Snacks Preparation, Eating, Cleanup</p>	<p>Caregiving Dressing, Diaper Change, Bath, Washing Hands, Brushing Teeth</p>
<p>Book Sharing</p>	<p>Family Chores Mailbox, Laundry, Care for Pets, Plants</p>

Early Steps

- Randomized controlled trial
- Three sites: the M.I.N.D. Institute, UMACC, U Washington
- Comparing 25 hours a week, in home, therapist-conducted Early Start/Denver model to treatment as usual
- Multi-approach with high level of supervision (3 children/1 Ph.D./MA-BCBA)

Early is the better...

Early core deficits may lead to a cascading effect on neurodevelopment that arise from impoverished social interaction.

(Mundy & Burnette, 2005)



Underscores the importance of developmental interventions

ASD Video Glossary

Collaboration to develop a web-based video tool to illustrate the early signs of ASD, the screening and diagnostic process, and common interventions for families and professionals.



AUTISM SPEAKS™

www.autismspeaks.org



www.firstsigns.org



firstwords.fsu.edu

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**PART 2: Adaptation and
Accommodation in Adolescence
and Adulthood in ASD:
Individuals, Families and
Communities**

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Conflict of Interest

- Susan Risi, Andrew Pickles and I receive royalties from the publication of the ADI-R, ADOS and/or SCQ, three of the instruments used in the research I will discuss today. Any royalties generated from Michigan research or clinical work are donated to an autism-related nonprofit corporation as per agreement with University of Michigan.

Overview

Definition of Autism Spectrum Disorders
Legends about adolescence/adulthood in ASD
Commonalities
Differences in what adolescence and adulthood mean for ASD
Longitudinal studies
Changes in last few years
Back to legends
What is next?

Autism Spectrum Disorders

- Autism: Social and communication deficits and repetitive, restricted behaviors
- Asperger Syndrome: The social deficits of autism accompanied by fluent language (no history of language delay; nonverbal learning disabilities; milder social deficits)
- PDD-NOS: Similar deficits to autism but milder across the board or only social deficits and difficulties in one other area

General Issues

- Variability within ASD is huge, and this is never more apparent than during adolescence
- In adulthood especially, variability comes more and more not just from differences in language level and intelligence, but from comorbidities and personality features, as well as core features of ASD
- Generally, almost all individuals with ASD become more socially directed as they get older, though social difficulties still remain
- Behavior difficulties are not the norm, but are more common in ASD than language disorders

Legends in ASD

- Adolescence is always a time of deterioration and difficulty in ASD
- If a child with has not “recovered” by age 5, there is no chance he or she will do well as an adult
- 50% of children with ASD who have had intensive treatment will be normal by 5 and forever after
- Autism is defined across the lifespan by aloofness and lack of social responsiveness
- There is an ASD trajectory

- videos

Commonalities: Changes in adolescence

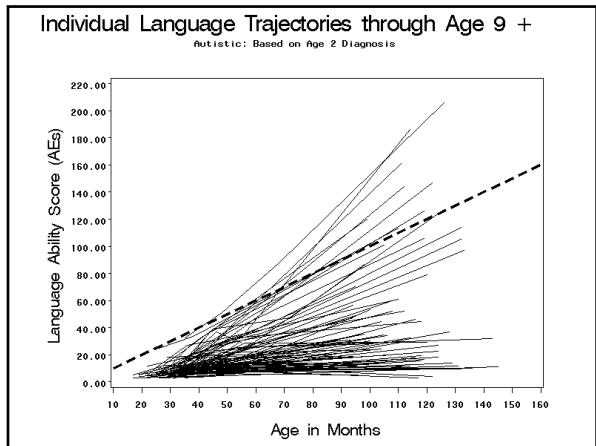
- Children get bigger
- Expectations for complex behaviors skyrocket, particularly with peers
- School becomes more language-based
- There is less support and structure
- Sexuality becomes more predominant
- Much cognitive growth occurs

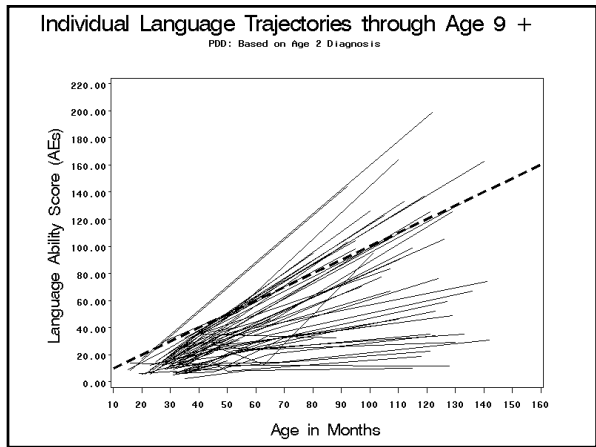
Differences for individuals with ASD

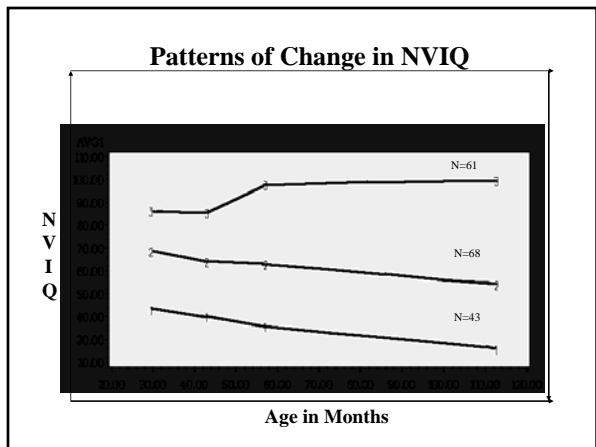
- Adolescence does not necessarily mean more social choices and increased freedom (but does mean added responsibility)
- I don't want to be 12!
- Adolescence may not be a time where skills are avidly pursued with friends
- **However, much of this does happen in young adulthood**

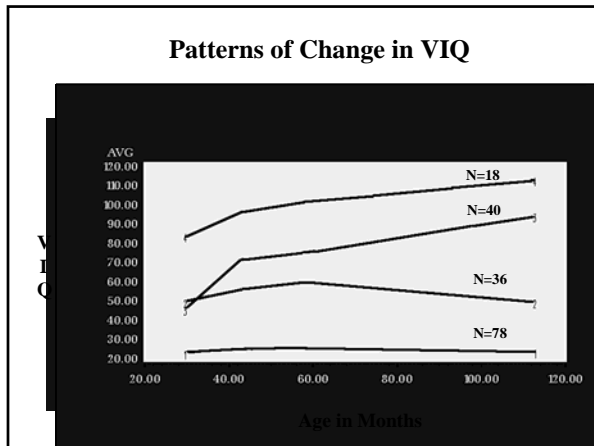
Longitudinal Study from 2 to 17

	Race (B/W) (%)	Gender (M/F) (%)	Mean Age in Mos. at First Test (SD)	Mean Age in Mos. at Last Test (SD)	Mean VIQ Age 9 (SD)	Mean NVIQ Age 9 (SD)
N. Carolina n=102	39/58	77/23	28.7 (4.8)	122.0 (8.3)	52.4 (39.3)	67.2 (23.6)
Chicago n=68	8/86	85/15	29.3 (5.6)	98.2 (10.9)	55.6 (37.6)	74.3 (18.1)









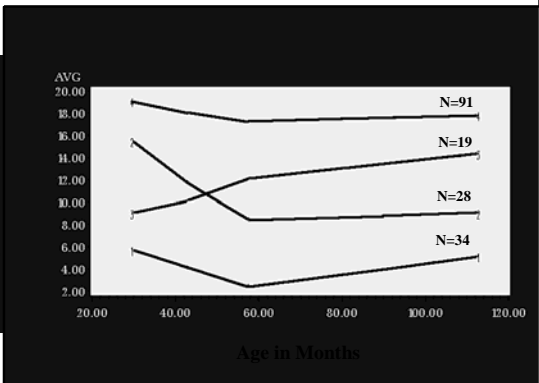
Estimates of Expressive Language Percent of 151 Participants

	Chicago	North Carolina
Complex sentences (ADOS Module 3)	40.9	39.6
Sentences but not fluent (ADOS Module 2)	35.3	28.9
Words but not sentences (ADOS Module 1; ADI-R = 1)	10.5	16.8
No or few consistent words (ADI-R=2)	14.3	14.4

Treatment effects

- The one treatment effect we found in this non-RCT sample was that children whose parents who worked with their child in some kind of formal way had higher verbal skills by the time they were 9.

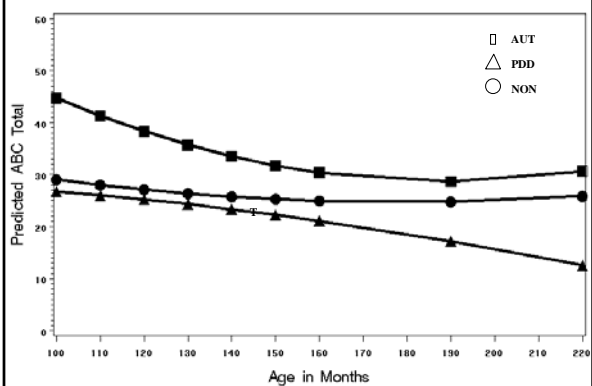
Patterns of Change in ADOS Algorithm Totals

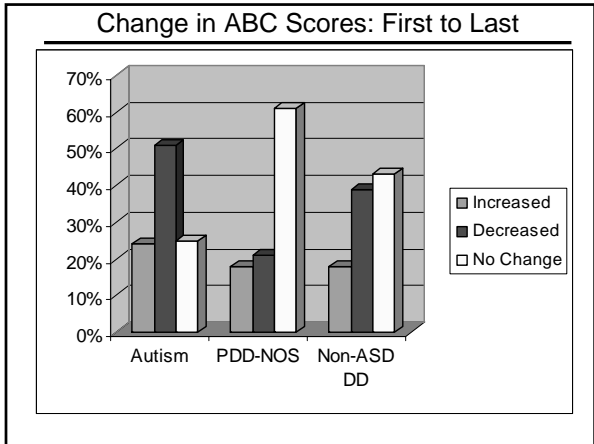


Best Estimate Diagnoses at 2 and Most Recent Assessment

		Most recent assessment		
		Autism	PDD-NOS	Nonspectrum
At 2 years	Autism	76	13	1
	PDD-NOS	27	11	6
	Nonspectrum	2	9	34

Behavior Problems from Age 9 to 18





- ### Changes in the few years
- Access to regular education
 - Better academic skills
 - More jobs
 - More social support
 - Driving
 - Identification as Asperger's or autism

- ### Legends in ASD
- Adolescence usually not a time of deterioration in ASD, though there is small proportion of students who have great difficulties
 - We do see real growth in skills and behavior after age 5 and into adulthood, particularly in people with PDD-NOS
 - Of children with autism, only 1% moved out of the spectrum by 9 and perhaps another 1% by 17; there was no relationship between treatment and "recovery" though there was a relationship between parents' participation in treatment and verbal skills
 - Most individuals with ASD were not aloof and increased in social interest by adolescence
 - There is not a single ASD trajectory

Continued issues

- Access to adequate services
- Combination of high repetitive behavior, aggression, poor adaptive skills
- Comorbidity with depression, ADHD, OCD; anxiety disorders -- not usually schizophrenia (more associated with mildest cases)
- Executive functioning, motivation, initiative
- Importance of a social network from preschool through adulthood and the importance of families

Collaborators

- Deborah Anderson, Michigan
- Andrew Pickles, Manchester
- Elizabeth Buvinger, Michigan
- Susan Risi, Michigan
- Cory Shulman, Hebrew University
- Pamela DiLavore, UNC
- Kaite Gotham, Michigan
- And nearly 200 parents and individuals with ASD

There is much good in store in the future for adolescents and young adults with ASD today, but many more services are needed.

**University of Michigan Autism and
Communication Disorders Center (UMACC)/
New York Child Study Center**
