Engaging Families of Children with Developmental Disabilities in Early Detection, Early Intervention, and Prevention

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Keynote Presentation at the National Academy of Sciences’ Workshop on Strategies for Scaling Tested and Effective Family-Focused Preventive Interventions to Promote Children's Cognitive, Affective, and Behavioral Health
April 2, 2014
Washington, DC
Problem: The estimated lifetime society cost is $3.2 million per child with autism

Autism spectrum disorder is no longer uncommon
1 in 68 children– 1 in 42 boys, 1 in 189 girls

The median age for diagnosis of ASD in the US is ..... over 4 years of age

Intervention has the greatest impact on autism if .... it begins before 3 years of age

There is a federal mandate for early intervention, but 80% of children who need early intervention are missed.

(CDC, 2014; NRC, 2001; USDOE, 2012)
Need to Improve Early Identification of Developmental Disabilities

Percentage of Population Receiving Special Education or Early Intervention Services in 2007:

- School-Age Children
  6 to 17 years  11.4%

- Preschool Children
  3 to 5 years  5.7%

- Infants and Toddlers
  Birth to 2 years  2.5%

### Percentage of students ages 6-21 served under IDEA


<table>
<thead>
<tr>
<th>Disability Category</th>
<th>% Served</th>
</tr>
</thead>
<tbody>
<tr>
<td>Specific Learning Disabilities</td>
<td>43.6</td>
</tr>
<tr>
<td>Speech or Language Impairment</td>
<td>19.2</td>
</tr>
<tr>
<td>Other Health Impairments</td>
<td>10.5</td>
</tr>
<tr>
<td>Intellectual Disabilities</td>
<td>8.3</td>
</tr>
<tr>
<td>Emotional Disturbance</td>
<td>7.3</td>
</tr>
<tr>
<td><strong>Autism</strong></td>
<td><strong>4.3</strong></td>
</tr>
<tr>
<td>Multiple Disabilities</td>
<td>2.2</td>
</tr>
<tr>
<td>Developmental Delay</td>
<td>1.5</td>
</tr>
<tr>
<td>Hearing Impairments</td>
<td>1.2</td>
</tr>
<tr>
<td>Orthopedic Impairments</td>
<td>1.0</td>
</tr>
<tr>
<td>Visual Impairments</td>
<td>0.4</td>
</tr>
<tr>
<td>Traumatic Brain Injury</td>
<td>0.4</td>
</tr>
<tr>
<td>Deaf-blindness</td>
<td>0.03</td>
</tr>
</tbody>
</table>
Where do we draw the line?

2\textsuperscript{nd} percentile is too low to detect the 11.4\% who will be eligible for special education at school age in time for early intervention.
Why worry about early literacy skills?

(Good, Simmons, & Smith, 1998)

Reading trajectories are established early.
Established reading trajectories are difficult to change. (Good, Simmons, & Smith, 1998)

Poor readers begin with lower scores and progress at slower rates.
Traditional reading tests identify reading trajectories too late.

(Good, Simmons, & Smith, 1998)
Preschool Emergent Literacy Predictors of Reading Problems

(Lonigan, Burgess, & Anthony, 2000)

- Phonological Sensitivity
- Print Knowledge
- Spoken Language
30 Million Word Gap

(Hart & Risley, 1995; 2003)

Cumulative differences in language experiences may be insurmountable by age 4.
Vocabulary growth trajectories are established early. (Hart & Risley, 1995; 2003)

Widening Gap in Vocabulary Growth by Age 3
School readiness efforts need to begin earlier

- A child’s rate of language acquisition is solidified by 2 to 3 years of age and is correlated with IQ and school success.

(Hart & Risley, 1995; 2003; Walker, Greenwood, Hart & Carta, 1994)
Based on a study of 1,300 students with disabilities 6-9 years of age from 180 school districts:

“Research shows that there is a strong correlation the number of hours that a student spends in the general education classroom and achievement outcomes for both reading and math.”

(Cosier, Causton-Theoharis, & Theoharis, 2013)
Which child will have challenges learning to read and write?
We can predict from their writing samples at 4 years of age.
We can predict from their drawing samples 3 years of age.
We can predict from their social communication profiles at 20 months of age.
Instead of waiting to see if a child is delayed in language and at risk for reading problems, it is possible to evaluate skills that are early predictors of language development.
FIRST WORDS Project
Longitudinal Research Project
Funded by US DOE, NIDCD, NICHD, and CDC

firstwords.fsu.edu

Amy M. Wetherby, Ph.D.
Project Director
Research has identified a collection of 8 predictors of language learning.

(Watt, Wetherby, & Shumway, 2006; Wetherby et al., 2003; 2007)

- Share attention and interests
- Rate of communicating
- Reasons for communicating
- Inventory of gestures
- Inventory of sounds
- Understanding words
- Play actions
- Book knowledge
Development of gestures at 9 to 16 months predicts language 2 years later

(Caselli, Rinaldi, Stefanini, & Volterra, 2012; Rowe & Goldin-Meadow, 2009; Watt, Wetherby, & Shumway, 2006)

Children should use at least 16 gestures by 16 months.
The richest moments for early language learning are when...

1. the child and caregiver are sharing attention, and

2. the caregiver talks about the child’s focus of attention.

(Landry, Smith, Swank, & Guttentag, 2008)
A child’s social communication skills—as shown here in the use of gestures and knowledge that pictures in the book convey information to share—provide critical opportunities for the caregiver to be responsive and moments for language learning. Delays in social communication impact the language learning environment.
How early can we detect autism?
Smart ESAC to streamline screening

Early Screening for Autism & Communication Disorders

- Online automated scoring at well-child checkups
  - Best 10 questions to sort out TD
  - Best additional 20 questions to sort out ASD and DD
- Algorithms for 12-18, 18-24, 24-36 months
- Se .88, Sp .81; AUC .92

Funded by NIH/NICHD

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**SORF** - new observational screening tool

Systematic Observation of Red Flags of Autism Spectrum Disorder

The SORF is an observational screening tool. We are testing cut-off scores for use in clinical and home observations.

In the next slide, you can preview a pair of videos that compare a child with typical development & a child with red flags of ASD.

These videos are from About Autism, our first Autism Navigator tool for the public, that will be launched in Summer, 2014.

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**Table:**

<table>
<thead>
<tr>
<th>A. Impairment in Social Communication and Social Interaction</th>
<th>B. Restricted and Repetitive Patterns of Behavior, Interests, or Activities</th>
</tr>
</thead>
<tbody>
<tr>
<td>1. Deficits in Social-Emotional Reciprocity</td>
<td>1. Repetitive and Stereotyped Behavior</td>
</tr>
<tr>
<td>- Limited sharing warm, joyful expressions</td>
<td>- Repetitive movements with objects</td>
</tr>
<tr>
<td>- Flat affect or reduced facial expressions</td>
<td>- Repetitive movements or posturing of body</td>
</tr>
<tr>
<td>- Limited sharing interests and enjoyment</td>
<td>- Repetitive speech or intonation</td>
</tr>
<tr>
<td>- Lack of response to name or social bids</td>
<td>- 2. Excessive Adherence to Routines and Ritualistic Behavior</td>
</tr>
<tr>
<td>2. Deficits in Nonverbal Communication Used for Social Interaction</td>
<td>- Ritualized patterns of behavior</td>
</tr>
<tr>
<td>- Poor eye gaze directed to faces</td>
<td>- Marked distress over change</td>
</tr>
<tr>
<td>- Limited use of conventional gestures—showing and pointing</td>
<td>- 3. Restricted, Fixated Interests Abnormal in Intensity or Focus</td>
</tr>
<tr>
<td>- Uses person’s hand/body as a tool without gaze</td>
<td>- Excessive interest in particular objects, actions, or activities</td>
</tr>
<tr>
<td>- Limited use of consonant sounds in vocal communication</td>
<td>- Clutches particular objects</td>
</tr>
<tr>
<td>- Limited coordination of nonverbal communication</td>
<td>- Sticky attention to objects</td>
</tr>
<tr>
<td>3. Deficits in Relationships with People Other than Caregivers</td>
<td>- Fixed interests on parts of objects</td>
</tr>
<tr>
<td>- Less interest in people than objects</td>
<td>- 4. Hypo- or Hyper-Reactivity to Sensory Input or Unusual Sensory Interest</td>
</tr>
<tr>
<td>- Limited sharing of imaginative play</td>
<td>- Lack of or adverse response to specific sounds, textures, or other sensory stimuli</td>
</tr>
</tbody>
</table>

Adapted from the DSM-5 Diagnostic Criteria for ASD (American Psychiatric Association, 2013)
Click to watch each video. (Internet connection required)
Community-viable intervention model for toddlers with ASD & their families

Funded by NIMH and Autism Speaks

Teach parents how to use supports and strategies in everyday activities at home and in the community
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)
RCT of Early Social Interaction (ESI) Project

82 children entered study at 18 months with diagnosis of ASD
Compared effects of 2 parent-implemented intervention conditions (9 months)

- **Individual ESI**
  - High Intensity
  - 3 individual sessions per week (2 at home and 1 in clinic playroom); reduced to 2 sessions per week in last 3 months

- **Group ESI**
  - Low Intensity
  - 1 group session per week (1 education meeting and 3 playgroup sessions per month)

Employed a crossover design so that all families received both treatments.
The 3 Layer Cake:

*Teaching strategies & supports to parents to promote child active engagement in everyday activities*

**Supports for better skills**
- Model and build language, play & interaction
- Extend activity, child’s roles, & transitions
- Adjust expectations & supports
- Balance of interaction and independence

**Supports for social reciprocity**
- Promoting initiation
- Balance of turns
- Natural reinforcers
- Clear message to ensure comprehension

**Supports for a common agenda**
- Motivating activity
- Productive roles
- Predictability
- Positioning
- Follow child’s attentional focus

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“Everyday Activity Categories” to promote learning in the natural environment

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

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Next Steps

- Sorting out active ingredients of treatment and treatment responders
- Collaborating with Dr. Ami Klin, PI of the Emory Autism Center of Excellence, to study the effects of ESI with younger sibs starting at 12 months
- Comparing mobile coaching with face-to-face coaching and combinations of the two
- Developing treatments that are feasible for families of diverse cultures and communities of modest resources
- Studying community implementation strategies to bridge gap between research and common practice in both early detection and early intervention
Push-Pull: Building the Capacity of Communities to Improve Early Detection & Access to Care

Primary Care Physicians

Early Intervention Providers

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Leveraging the Laws of Motion to Generate Forward Movement:  
*We need all 3 wheels for balance and acceleration.*
IF A PICTURE IS WORTH A THOUSAND WORDS, IMAGINE WHAT A VIDEO IS WORTH.

To learn about Autism Navigator, go to www.whyautismnavigator.com

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We launched the ASD Video Glossary in 2007. You can explore it at: www.autismspeaks.org/what-autism/video-glossary
Collection of Web-based Tools & Courses
to Bridge the Gap between
Science and Community Practice

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With funding from 4 founding states- FL, PA, TN, & GA- we developed this 30-hour professional development course for early intervention providers. It is being deployed in these 4 states.

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This 6-hour course is under development. We will begin deployment in the Summer, 2014.
The Autism Navigator for Primary Care includes access to the Smart ESAC for universal screening for communication delay and autism between 12 and 26 months of age.
Current Courses

✓ for Early Intervention Providers (30 hours)
  ▪ State Department of Education or Health

✓ for Primary Care (2 to 6 hours)
  ▪ Private Insurance, Medicaid, WIC, Military

Future Courses

✧ for Kindergarten Classrooms (20 hours)
✧ for Head Start and Early Head Start
✧ for Early Education and Child Care, VPK, and Preschool Education
ASD Video Glossary
About Autism

Future Tools

✧ Social Communication “Growth Charts” App
✧ “How to” Guide for Families
✧ Going out to Everyday Places
  Grocery stores, restaurants, parks, libraries, department stores, religious or public gathering places, theme parks, out-of-town travel by plane, bus, or train
  ▪ App for Families and Course for Employees
✧ “GPS” after the Diagnosis

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About Autism, our first tool for the public, will be launched in Summer, 2014. In the next two slides, you can preview videos from About Autism.

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Click to watch video on the early signs of autism. (Internet connection required)
Click to watch video of LB’s change with intervention. (Internet connection required)
Most parents and professionals are familiar with early motor milestones. However, few know the social communication milestones, which offer a critical window into an infant’s well being and are the earliest signs of healthy development and school readiness.
Social Communication Growth Charts

with video to illustrate the milestones and provide tips to promote development
“How To Guide”

for families of toddlers suspected of ASD

Interactive web-based program with video illustrations

Teaching Strategies and Supports: The 3 Layer Cake

- Supports for Shared Agenda
- Supports for Social Reciprocity
- Supports for Better Skills

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Autism Navigator E-Co-System

Autism Navigator for Primary Care
• *Smart ESAC universal screening*

Autism Navigator for Early Intervention Providers

Tiered Early Care Supports and Services

Self-Guided Digital Family Tools

- Social Communication Growth Charts
- About Autism
- “How To Guide”

Maximize use of technology

- Monthly Group E-Meetings
- Weekly Group Live Meetings
- Weekly Individual Enhanced Home Visits

Monthly E-Monitoring

Child’s Age in Months

9 12 15 18 21 24 27 30 33 36

*(Adams, Tapia, & the Council on Children with Disabilities, 2013)*

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CLINICAL REPORT

Early Intervention, IDEA Part C Services, and the Medical Home: Collaboration for Best Practice and Best Outcomes

Richard C. Adams, MD, Carl Tapia, MD, and THE COUNCIL ON CHILDREN WITH DISABILITIES

KEY WORDS
Part C, IDEA, medical home, children with special health care needs, CSHCN, collaboration, comanagement, coaching, learning in the natural environment

ABBREVIATIONS
AAP—American Academy of Pediatrics
EI—early intervention
IDEA—Individuals With Disabilities Education Act

abstract

The medical home and the Individuals With Disabilities Education Act Part C Early Intervention Program share many common purposes for infants and children ages 0 to 3 years, not the least of which is a family-centered focus. Professionals in pediatric medical home practices see substantial numbers of infants and toddlers with developmental delays and/or complex chronic conditions. Economic, health, and family-focused data each underscore the critical role of timely referral for relationship-based, individualized, accessible early intervention services and the need for collaborative partnerships in care. The medical home process and Individuals With Disabilities Education Act Part C policy both support nurturing relationships and family-centered care; both offer clear value in terms of economic and health outcomes. Best practice models for early intervention services incorporate learning in the natural environment and coaching models. Proactive medical homes provide strategies for effective developmental surveillance, family-centered resources, and tools to support high-risk groups, and comanagement of infants with special health care needs, including...
Business Model Like Newman’s Own

- Provide free tools and resources for the public
- Certification courses for professionals
- Profits reinvested in research and development
- This model will promote scalability and sustainability
Early is the key...

- *Catching up* is very difficult for children on low reading and language trajectories once they get to school.

- The best solution is to help families early to support development in meaningful, everyday activities, so children are ready to learn when they enter preschool.
We have a critical window of opportunity to dramatically change the trajectory for our children in the first 3 years of life.
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(continued)

National Academy Press, Committee on Educational Interventions for Children with Autism, Division of Behavioral and Social Sciences and Education.


