Changing the Developmental Landscape for Autism Spectrum Disorders

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Center for Autism and Related Disorders
at Kennedy Krieger Institute
Today… The Children… Our World
Today’s topics

• Defining autism spectrum disorders
• Developmental landscape of ASD
  – Findings from prospective, longitudinal study
  – Early signs video tutorial
  – Novel means of early detection of risk for ASD
• Effectively educating children with ASD: Opportunity to change the developmental landscape
• Support options for parents, educators, and care-givers
Insights into Autism Spectrum Disorders
Autism: A disconnectivity syndrome

Defining ASD

- Social information processing
  - Understanding nonverbal social cues
  - Understanding others’ perspectives
  - Knowing how to reciprocate conversationally, socially
  - Anticipating consequences
  - Modulation of eye contact
  - ‘Reading’ scenes

- Communication processing
  - ‘Reading between the lines’ (innuendo)
  - Understanding non-literal language
  - Getting the ‘gist’
  - Concept formation
  - Linguistic flexibility
  - Narrative – especially re characters’ perspectives
Defining ASD

- ‘Sticky’ attention
- Unusual and intense interests
- Different sensory processing
- Difficulty with change in routine
First hand description of experience
“This is about building a life that we want.”
“I got as much strengths from my brain as I did challenges. It has been hard to develop those things [challenge areas] in practice that they [the challenges] would have the meaning that I and others would like them to.”
One of my tendencies as a person on the autism spectrum is to go through emotional perseveration. I have an emotional response and it keeps going. It is ruthless until you solve it or otherwise dissipate it.

I have taken cognitive approaches ... the other way is to use mindfulness, mind-body approaches... that has been more helpful. [Need both approaches.] What I do now...say I have a lot of adrenaline in me where I feel it in my body. I go where I notice it. I pay attention to the places in my body where I don't notice much of anything, where I feel blank. I try to let those experiences come and not try to suppress it. I try to let it go through extinction and not reinforcement. I feel one sense of emotion then that clears and I move to another one and another one and eventually that clears.”
What can a teacher do to help?

Michael’s suggestions:
• Realize that processing is a real issue.
• Student needs to just go through these emotions and cool down.
• Recognize difficulty and reduce difficulty.
• Can you still achieve the objective with less homework?
Prospective, longitudinal research
- Infant siblings of children with ASD (high risk for ASD)
- Infants with no siblings with ASD (low risk for ASD)
- Preterm infants (increased risk for developmental delay)
Assessment ages

High Risk (HR for ASD; other DD)
Low Risk (LR)

Outcome Diagnosis

Rate confidence of presence of ASD at each age
Outcome classifications

Autism Diagnostic Observation Schedule + Clinical judgment

36 months

ASD

Intermediate

Unaffected
Developmental landscape

Degree of Atypicality
Patterns

• Most infants later diagnosed with ASD seem pretty typical through mid infancy
  – Except motor (postural control, grasping), possibly sensory, temperament; not ASD specific

• By late infancy, alterations appear in social initiation via gaze (roots of joint attention); also communication delays. Not ASD specific.

• At 14 months, most who go on to have ASD show some sort of delay
  – ~half with ASD are identifiable
  – ~half will show a later onset of ASD signs
  – Some who show ASD signs get ‘better’ and don’t develop ASD
Plateau in Language Development: Raw scores

- All groups score WNL at 6 months
- Absence of typical language growth spurt in ASD
- Virtual plateau in Early dx group

Landa, Gross, Stuart, Faherty. (2013). Child Development
Landa, Gross, Stuart, Faherty. 2013. Child Development
14-month Signs of ASD Risk

- Poor eye contact (except when tickled)
- Reduced self-generated social smiling
- Reduced self-generated social bids for others’ attention
- Reduced response to others’ bids for joint attention
- Infrequent response to name
- Language delay
- May show stereotypic behaviors; odd play
Sensitivity of parent report: Shows need for direct assessment of child

Hess & Landa, 2011 JADD
Hi Becky,

Just wanted to let you know that an alumnae of my alma mater, XXX College, used the early signs video over the weekend as she processed some concerns about her son. She reached out to a parents board we are both members of with her concerns, and not fewer than 3 other alums recommended the videos as a tool in addition to making very helpful suggestions for evaluation and discussing the benefits of early intervention. The videos are definitely out there in the wide world doing good work and it was wonderful to see them helping a member of my community so directly.
Neuroplasticity – Impact of Early Intervention
Early Intervention

• Developmental enrichment for all infant-toddler siblings of children with ASD

• Emphasize:
  – Self-generated action (motor)
  – Highly motivating & rewarding to child (child responsive)
  – Routines-infused (Hebbian principle, predictability)
  – Supporting families – using adult learning models
Early Achievements Pre-Treatment Data

<table>
<thead>
<tr>
<th>Domain</th>
<th>Non IS mean (sd) (n=25)</th>
<th>IS mean (sd) (n=24)</th>
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</thead>
<tbody>
<tr>
<td>Age</td>
<td>28 (2.7)</td>
<td>27 (2.9)</td>
</tr>
<tr>
<td>Visual Reception</td>
<td>31 (11.6)</td>
<td>27 (8.8)</td>
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<tr>
<td>Receptive Language</td>
<td>22 (7.2)</td>
<td>24 (9.7)</td>
</tr>
<tr>
<td>Expressive Language</td>
<td>24 (7.0)</td>
<td>23 (6.1)</td>
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</tbody>
</table>

Landa, Holman, O’Neill, & Stuart, 2011, JCPP
IS group made significant gains in frequency of IJA ($p<.01$) and shared positive affect (CSBS DP) ($p<.05$)
EI is important because

• Early experiences influence brain development

• The brain is a thinking organ
• It learns and grows by interacting with people and objects, through perception and action
• Able to continually adapt and rewire itself
• Constraints – need good intervention
Innovation and Impact

Model development

Model evaluation

Model dissemination
Example: Within a specific focus

Targeted Early Intervention (2-yr olds) RCT

Classroom-based

Parent-implemented

IES Baltimore County

More Model development: face processing

Baltimore County IT

‘control’ in RCT examining new EA model

Parent Training

Center for Autism and Related Disorders
at Kennedy Krieger Institute
Federally funded studies in public schools and Infants and Toddlers

- Parent-implemented early intervention for children with ASD in low SES minority homes (HRSA AIR-B)
- Developing friendships and social skills in school-based settings (HRSA AIR-B)
- Multiple Baseline Single Subject Design of 5- to 8-year-olds seen for 1 hour per week, four days per week for six months at school (NIH)
- RCT: Minimally verbal 3- to 5-year-olds 5 days per week at school for 6 months (NIH)
- RCT: Infants and Toddlers providers being trained in Evidence-Based Practices in parent-implemented intervention (HRSA)
• **Early Achievements model** – NIH – designed to target core deficits of ASD in toddlers (Landa et al., 2011; Landa & Kalb, 2012)

• Redesign for feasible and scalable implementation by teachers in public preschools (inclusive and non-inclusive settings)
9th Biennial Conference on Research Innovations in Early Intervention (CRIEI) 2014

A forum for those involved in all aspects of research on children with disabilities, birth to 8 years, and their families

February 20-22, 2014
Hyatt Regency Mission Bay, San Diego, CA
Findings across groups: Somber news

• Teachers are having great difficulty reaching fidelity on evidence-based instruction measures
• Training teachers to fidelity takes much creativity in the training design
• Intensive training is needed for ‘small’ Gains in new knowledge/implementation
Many factors impact a teacher’s instructional behavior:

- Complexity of children
- System-chosen curriculum
- Number of children
- Training and support given to administer the curriculum
- Parent issues
- Holidays, snow days, consistency of attendance
And evidence-based practices must be integrated with fidelity?

- Developmentally appropriate goals
- Embedded instruction
- Motivating and engaging students
- Well engineered classroom
- Monitoring progress
- EB instructional strategies
- Differential instruction
- Adhere to curriculum
Achievement
Our goals are to equip teachers to help children learn more, more effectively, and more efficiently

• Concept development
• Social cognition and peer engagement
• Language and purposeful communication
• Reduce or eliminate maladaptive behavior
• Improve attention to relevant salience
• Generalization of knowledge

• Learning and reduced need for special education supports
Training IAs and teachers

IES:
• 6 days of didactic and interactive training
• In-classroom coaching with fidelity checks and feedback

MSDE Technical Assistance:
• Eastern Shore
• Less intensive training
IES: Training the teachers of Baltimore Co
Book Sharing Protocol: Easy Delivery of Active ingredients

- Embodied cognition
- Concept formation
- Active engagement
- Focused attention
- Planful search
- Social cognition
- Language
- Literacy
- Much more
Principles implemented in public schools
Children’s data

- Significant improvement in all areas
September 2014: Started the RCT in Baltimore County Public Schools
This is about shaping children’s destinies
Pearls of Wisdom from Michael Shor

• “After going to a small private school since preschool, I went to school at a public junior high school, where I experienced severe stress and anxiety, as well as depression.”

• “I had very limited relationships with people at school, and I was subject to bullying and social harassment.”

• “…problems with academics and the structure of school work … were a basis for schools providing work that did not really educate me to the level that matched what I was otherwise capable of.”
  – Variation in developmental profile- at what level is education pitched? At what level do peers ‘match’?
• “I left Junior High because of daily migraines and burnout, due to problems with the school environment.”
• “I was home-schooled, and most of my education occurred through independent study.”
Supporting parents, teachers, administrators
The field of education

- Lessons from autism - implications for children with other disabilities
- Teacher training
- Pre-service preparation
- Curriculum – considerations for children with autism
- Implications for a lifetime
  - Quality of life
  - Fulfillment
  - Emotional well-being and sense of self
  - School experience
  - Employability and employment options
  - Behavior
Change

READY FOR CHANGE
Must be

- Informed
- Strategically planned and implemented
- With GREAT CARE
- Need more bottom up
- Beware of trends
- Science matters but beware of the emperor's new clothes
Which have implications for

- Resource utilization
- Determining policy
- And $
Ready to launch to next level

Together, we are powerful.

We can change the world.
So much more is possible
Insights: Personal stories

- Ms. Deborah Page: Mother of a son on the spectrum
- Ms. Jamie Haugh: Special Educator, BCPS
- Mr. Tom Whalen: Self Advocate
Thank you