NIH push for translational research: The dawn of Implementation Science

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Conflicts of Interest

No conflicts of interest associated with this presentation

On behalf of Dr. Alice Kau & NICHD

Autism Research Update

Alice Kau, Ph.D.

Intellectual and Developmental Disabilities Branch

Eunice Kennedy Shriver National Institute of Child Health and Human Development (NICHD)

National Institutes of Health (NIH)

National Autism Conference

State College, Pennsylvania

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Alice Kau, PhD

Stay Connected to NIH

NIH Director's Blog-

http://directorsblog.nih.gov/

IACC, Dr. Tom Insel

Interagency Autism Coordinating Committee (IACC)

Federal advisory committee that coordinates all efforts within the Department of Health and Human Services (HHS)

Thomas Insel, MD

Established by Congress under the Children's Health Act of 2000, reconstituted under the Combating Autism Act (CAA) of 2006, and renewed under the Combating Autism Reauthorization Act of 2011.

IACC questions determining priorities for research

- #1: When should I be concerned?
- #2: How can I understand what is happening?
- #3: What caused it to happen and can it prevented?
- #4: Which treatments and interventions will help?
- #5: Where can I turn for services?
- #6: What does the future hold, particularly for adults?
- #7: What other infrastructure and surveillance needs must be met?

IACC most recent priorities

Translation !

Translation !

Translation !

Translation !

Translation !

NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development

IACC Released the 2013 strategic plan update

- Encouraged more attention to the needs of adults with ASD
- More focus on the most disabled individuals and underserved populations
- Need for interventions for co-occurring conditions
- Developing efficacious, efficient, scalable, and cost-effective interventions, tools, and practices
- Need for interventions that can improve quality of life for individuals with ASD and their families

Tangible Achievements in Advancing Well-Being of individuals affected by autism and their families

IACC: Addressing Autism as a Public Health Challenge

NIH Eunice Kennedy Shriver National Institute of Child Health and Human Development

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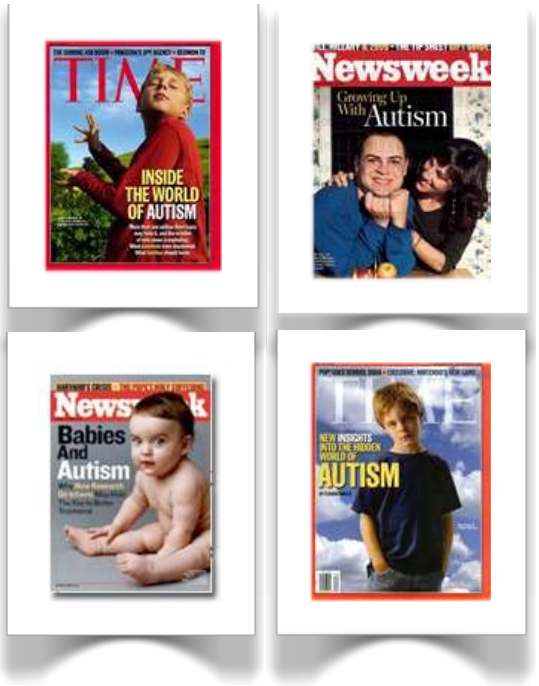
Autism as a Public Health Challenge

- Prevalence: 1 : 68 [1:42 in boys]
- Community Disparities (dx; access)
- Societal Cost/Year in the US: $ 136 billion
- Lifetime Cost of Care Per Child: $ 2.4 million
- Despite strong genetic bases, diagnosis is behavioral, reference standards excellent (ADI-R/ADOS/expert clinician)
- Majority of autism diagnoses in US outside academic medical centers
  - ✳ usage of ADI-R and ADOS in fewer than 0.1% and 2.1%, respectively
  - ✳ questionnaires/checklists in 30%



CDC, 2014; Peacock et al., 2012; Cidav et al., 2012; Mandell et al., 2013; 2014; Wang et al., 2013; Buescher et al., 2014; Wiggins et al., 2006

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Challenges and Opportunities:
Reducing Age of Diagnosis & Improving Access to Care

- Brain disorder of genetic origins
- Adverse outcomes can be attenuated
- Importance of early diagnosis and intervention for lifelong outcome and cost of care
- American Academy of Pediatrics
  - Screening (18 and 24 months), but still low uptake
- 8% of primary care providers routinely screen for ASD
- Median age of diagnosis in US: 4-6 to 5.7 years
- Later still in disadvantaged communities
- No Community-viable system of care
- Reimbursement systems NOT in place

Johnson & Myers, 2007; Dosreis et al., 2006; Heidgerken et al., 2005; Honigfeld et al., 2012; Shattuck et al., 2009; Mandell et al., 2005; 2009

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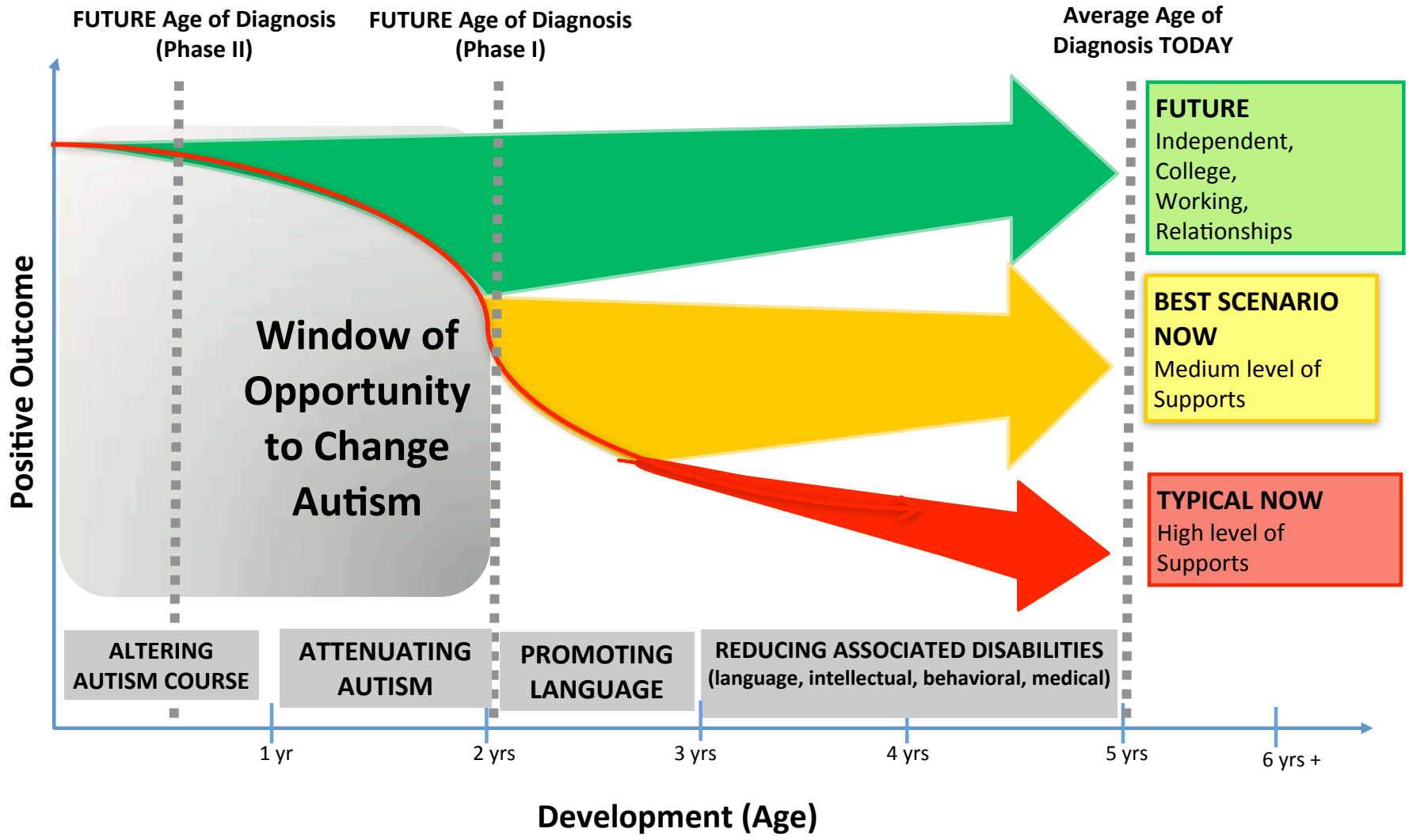
The importance of early identification & treatment: altering the life course of children



The Big Challenge: from Efficacy, to Effectiveness, to Uptake & Dissemination

- Formidable gap between innovations in health and their delivery to communities ... [the oft-quoted "10-year gap"]

- EFFICACY - EFFECTIVENESS - UPTAKE & DISSEMINATION

- Why is effective implementation such an intractable problem?
  - ✦ Because implementation has not been addressed through a research agenda
  - ✦ Although randomized controlled experiments are the gold standard for testing safety and efficacy, health delivery schemes are less likely to be subject to rigorous scientific analysis
  - ✦ The nature of the healthcare system, the stakeholder's motivations, satisfaction and behavior, the culture-specific norms, etc., are not made subject of science

What needs to be conquered

- TRANSLATIONAL ROADBLOCKS: The implementation gap
  - ✦ Barriers to rapid, efficient progression of innovations from basic science to clinical application to routine use

- TRANSLATIONAL ROADBLOCKS: Quality chasm
  - ✦ Gaps in quality, safety equity, efficiency, timeliness, and patient-centeredness of health care delivery

Dr. Brian S. Mittman

What is Implementation Science

- Implementation Science is the study of methods to promote the integration of research findings and evidence into healthcare policy and practice.

- Implementation Science seeks to understand the behavior of healthcare professionals and other stakeholders as a key variable in the sustainable uptake, adoption, and implementation of evidence-based intervention.

- Critical to the success of major policy initiatives in healthcare, education, and in any other point of intersection between science & healthcare policy and practice -- Achievement of societal goals.

What is Implementation Research

- The scientific study of methods to promote the systematic uptake of research findings and other evidence-based practices into routine practice, and hence, to improve the quality and effectiveness of health services

- It includes the study of influences on healthcare professional and organizational behavior

- It includes factors associated with the beliefs, intentions and behavior of stakeholders, cultural, societal and economic factors, and any additional factors that could potentially facilitate or hinder translation of evidence-based research into widely disseminated healthcare practice

Proctor et al., Administration & Policy in Mental Health and Mental Health Services Research, 2009; 36(1):24-34.

The Dawn of Implementation Science

BMC Health Services Research

BioMed Central

Study protocol

Open Access

PRIME – PRocess modelling in ImpleMEntation research: selecting a theoretical basis for interventions to change clinical practice

Anne E Walker[1], Jeremy Grimshaw[2], Marie Johnston[3], Nigel Pitts[4], Nick Steen[5] and Martin Eccles*[5]

Address: [1]Health Services Research Unit, University of Aberdeen, Aberdeen, UK, [2]Clinical Epidemiology Programme, Ottawa Health Research Institute, Ottawa, Canada, [3]Department of Psychology, University of Aberdeen, Aberdeen, UK, [4]Dental Health Services Research Unit, University of Dundee, Dundee, UK and [5]Centre for Health Services Research, University of Newcastle upon Tyne, UK

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* Corresponding author

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The Dawn of Implementation Science

Dr. Roger Glass

POLICYFORUM

14 DECEMBER 2007 VOL 318 SCIENCE www.sciencemag.org
Published by AAAS

PUBLIC HEALTH

Implementation Science

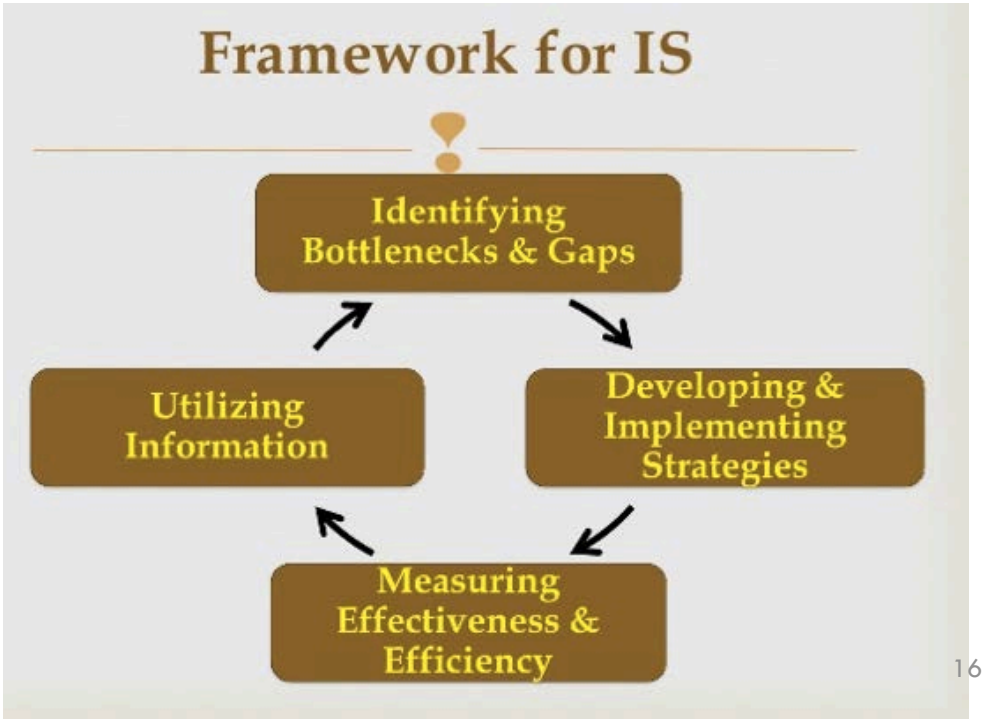
Temina Madon, Karen J. Hofman,* Linda Kupfer, Roger I. Glass

Researchers and funders need to use systems approaches that are beginning to translate research not only to the bedside but also to global health programs.

Global HEALTH

Implementation Science in HIV related work: Case study of Injection Drug Users Intervention in Tanzania

Jessie Mbwambo, Muhimbili National Hospital (MNH) and Muhimbili University of Health and Allied Sciences (MUHAS)



The Dawn of Implementation Science

Implementation Science catching speed in autism research

Dr. Craig Newschaffer

Dr. David Mandell

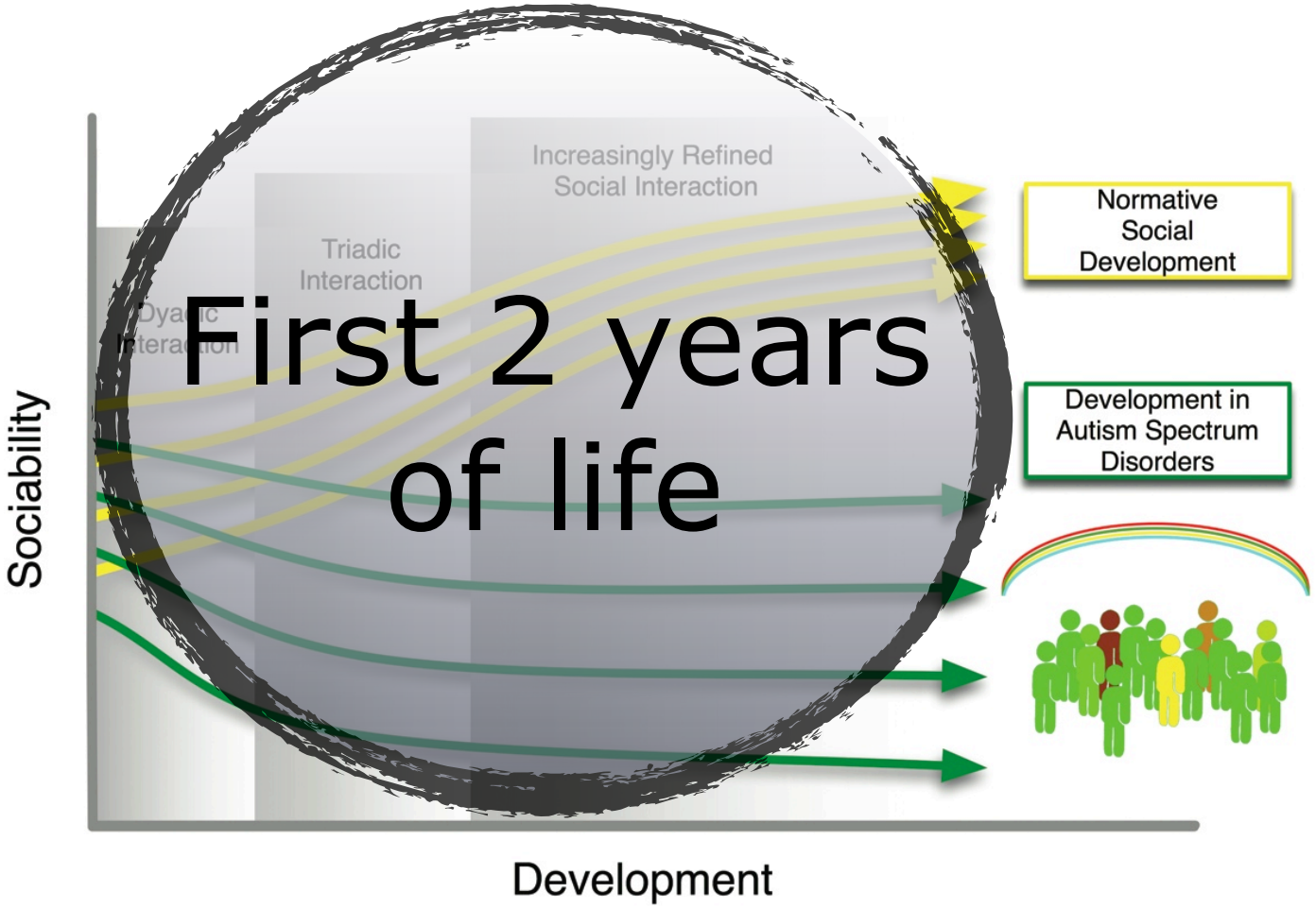
Dr. Paul Shattuck

Some of the mavens in autism-related Implementation Science & Research

GENETIC LIABILITY

MECHANISMS OF SOCIALIZATION

BEHAVIORAL SYMPTOMS



No Genetic Determinism

No Brain Determinism

JE LeDoux PhD

Jones et al. (2008). *Arch Gen Psy*, 65(8), 946-54; Klin et al. (2009). *Nature*, 459, 257-61; Jones & Klin (2009). *J Am Acad of Child Psy, 48(5): 471-3; Jones & Klin (2013). Nature*, 504, 427-431*; Klin et al. (2014). Neurosci Biobehav Rev.*

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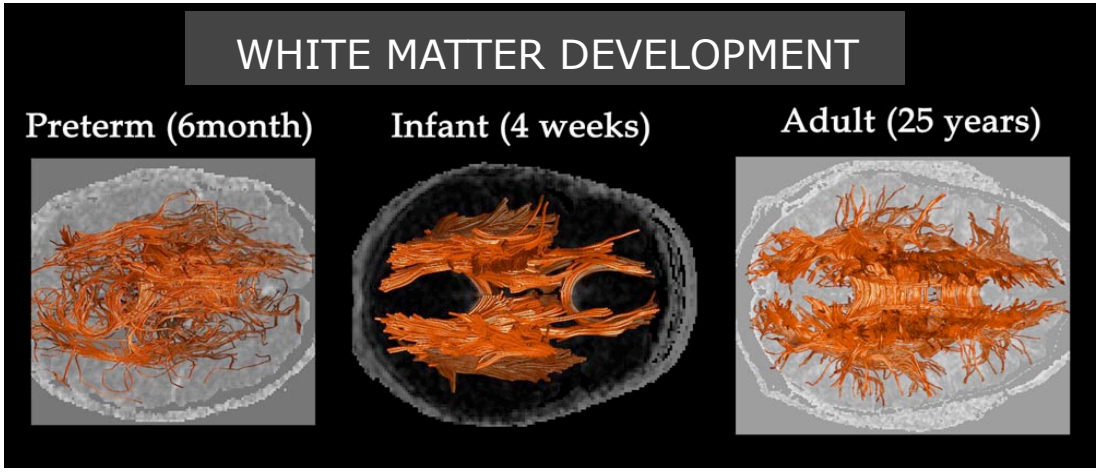
Autism Disrupts the Platform for Brain Development

Born to Socially Orient

MH Johnson PhD

Reciprocal Social Interaction

Neuroplasticity



H-J Park PhD

Developmental Trajectories

Developing expertise about the Social World

Developing expertise about the Physical World

Early Screening & Diagnosis: Challenges in Implementation

JOURNAL OF THE AMERICAN ACADEMY OF CHILD & ADOLESCENT PSYCHIATRY
VOLUME 53 NUMBER 2 FEBRUARY 2014 www.jaacap.org

REVIEW

Approaches to Enhancing the Early Detection of Autism Spectrum Disorders: A Systematic Review of the Literature

Amy M. Daniels, PhD, Alycia K. Halladay, PhD, Andy Shih, PhD, Lauren M. Elder, PhD, Geraldine Dawson, PhD

Dr. Amy Wetherby

Autism NAVIGATOR®

Smart ESAC

Dr. Diana Robins

M-CHAT™

- THREE PERSPECTIVES:
  - ✦ Informational Campaign
  - ✦ Routine Screening
  - ✦ Practice Enhancement

CDC CENTERS FOR DISEASE CONTROL AND PREVENTION

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A Bioethical Imperative: Access to Early Treatment - Promoting Social Engagement

Reciprocal Social Interaction

The Brain Becomes Who We Are....

JE LeDoux PhD

Early Intervention: Challenges in Implementation

(National Research Council, 2001)

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

"Less than 20% of children who will need special services in school in the US are identified before the age of 3 years"

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Mobilizing Community Systems

Family

Primary Care Physician

Early Intervention Provider

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Amy Wetherby, PhD

Jennifer Stapel-Wax, PsyD

COLLECTION OF TOOLS

About Autism

Early Intervention Providers

Primary Care Physicians >

Family Collection

Kids Health First

Children's Healthcare of Atlanta

Early Intervention Because... Babies Can't Wait

Bright from the Start
Georgia Department of Early Care and Learning

Autism NAVIGATOR™

Bridging the Gap Between Science and Community Practice

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Bridging the Gap Between Science and Community Practice

ABOUT AUTISM | ABOUT AUTISM NAVIGATOR | COLLECTION OF TOOLS | LOGIN/REGISTER

Autism Navigator™ increases the capacity of healthcare and early intervention providers, educators, and families to improve outcomes of young children with autism spectrum disorder (ASD).

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Early Intervention Providers

Primary Care Physicians >

Family Collection

Autism Navigator™ is a unique collection of web-based tools that uses extensive video footage to bridge the gap between science and community practice.

About Autism is a tool for families, professionals, or anyone interested in learning about autism spectrum disorder (ASD). It is available free of charge. Just register and login.

Launch About Autism >

OUR PARTNERS

Our partners are helping us make an impact on community practice.

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First Signs

Autism Science Foundation

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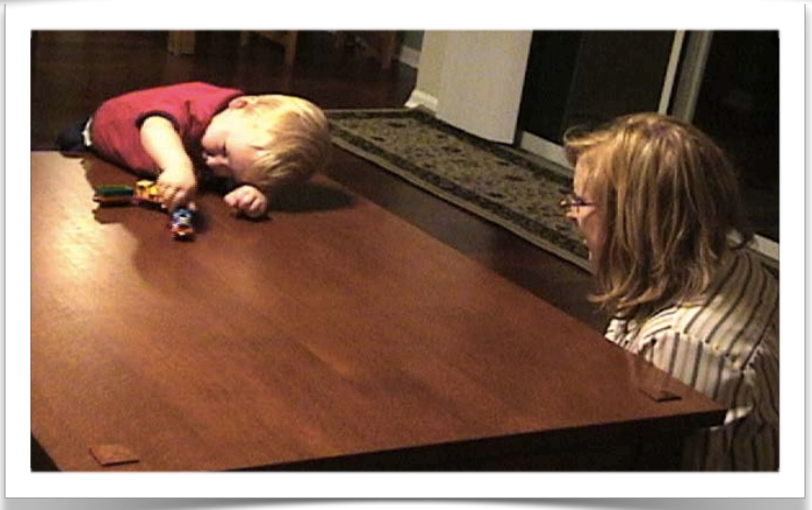
the Community: Families, Pediatricians, Early Intervention Providers



Parent-Delivered ESI

Wetherby et al., 2014

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Everyday Activities

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

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Treating deviations from normative social engagement: Parent-Delivered Social Interaction

Amy Wetherby, PhD

PEDIATRICS®
OFFICIAL JOURNAL OF THE AMERICAN ACADEMY OF PEDIATRICS

Parent-Implemented Social Intervention for Toddlers With Autism: An RCT

WHAT'S KNOWN ON THIS SUBJECT: Randomized controlled trials (RCTs) of intensive clinician-implemented interventions have demonstrated significant improvements in outcomes of toddlers and preschool children with autism spectrum disorder. RCTs of parent-implemented interventions have demonstrated improvements in parent skills, but generally they have not demonstrated effects on children's outcomes.

WHAT THIS STUDY ADDS: This RCT found significantly greater improvements with individual home coaching on child outcome measures of social communication, adaptive behavior, and developmental level. These findings support the efficacy of a parent-implemented intervention using little professional time, which increases potential community viability.

AUTHORS: Amy M. Wetherby, PhD,[a,b] Whitney Guthrie, MS,[b,d] Juliann Woods, PhD,[b,c] Christopher Schatschneider, PhD,[d] Renee D. Holland, MS,[b] Lindee Morgan, PhD,[a,b] and Catherine Lord, PhD[e]

Departments of [a]Clinical Sciences, [b]Autism Institute, [c]School of Communication Science and Disorders, and [d]Psychology, Florida State University, Tallahassee, Florida; and [e]Department of Psychiatry, Weill Cornell Medical College, New York, New York

KEY WORDS
autism, early intervention, toddlers, parent-implemented, outcomes

ABBREVIATIONS
ADOS—Autism Diagnostic Observation Schedule
ASD—autism spectrum disorder
CSBS—Communication and Symbolic Behavior Scales
EI—early intervention
ESI—Early Social Interaction

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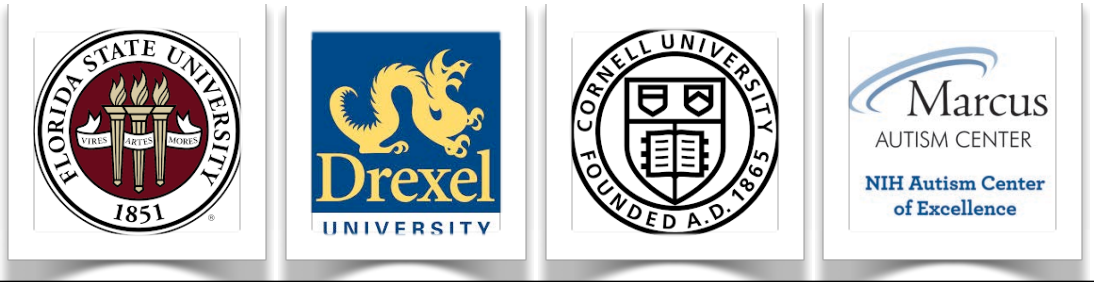
The road from efficacy to effectiveness is long: 36,000-children-in-4-states long

- To mobilize community systems:
  - 4 Academic Centers: FSU, Cornell, Drexell, Marcus Autism Center
  - Focus on Primary Care Providers enrolled via different systems of access
  - Tools: focus groups, satisfaction surveys, penetrance measures, moderator variables, etc.
  - Results, uptake, and measures of of successful screening, diagnostic evaluations, intervention, outcomes
  - Comparison of Methods of engagement
  - Comparison across systems, opinion makers
  - Impact on local policy and resources



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If this is our ultimate goal, implementation science and research should be our collective priority

To make autism
an issue of diversity,
not of disability