

Identification and Diagnosis of Autism Spectrum Disorder: A Research to Practice Panel Discussion

June 13, 2012



Presentation Overview

I. Introduction

Laura Kavanagh, MCHB

II. Presentations

Zachary Warren, Ph.D.

Laura J McGuinn, MD

III. Panel Discussion (Part 1)

IV. Presentations

Bruno Anthony, Ph.D.

Pasquale J. Accardo, M.D.

V. Panel Discussion (Part 2)

VI. Q&A

Please Take a Moment to Complete our Short Survey!



Welcome



Laura Kavanagh, MPP

Director, Division of MCH Workforce Development,
Maternal and Child Health Bureau





Improving Identification and Diagnosis of Children & Youth with Autism Spectrum Disorders through the Combating Autism Act Initiative

An Introduction to the CAAI Programs

Laura Kavanagh, MPP

Director, Division of MCH Workforce Development and
Autism Team Lead

June 13, 2012



Goal of the Combating Autism Act Initiative (CAAI)

Enable all infants, children and adolescents who have, or are at risk for developing, Autism Spectrum Disorders (ASD) and other developmental disabilities to reach their full potential by:



- **Developing a system of services that includes screening children early** for possible ASD and other developmental disorders;
- **Conducting early, interdisciplinary, evaluations** to confirm or rule out ASD and other developmental disorders; and,
- **Providing evidence-based, early interventions** when a diagnosis is confirmed.

Three Program Areas

**Autism
Intervention
Research**

Training

- DBP
- LEND

**State
Implementation**



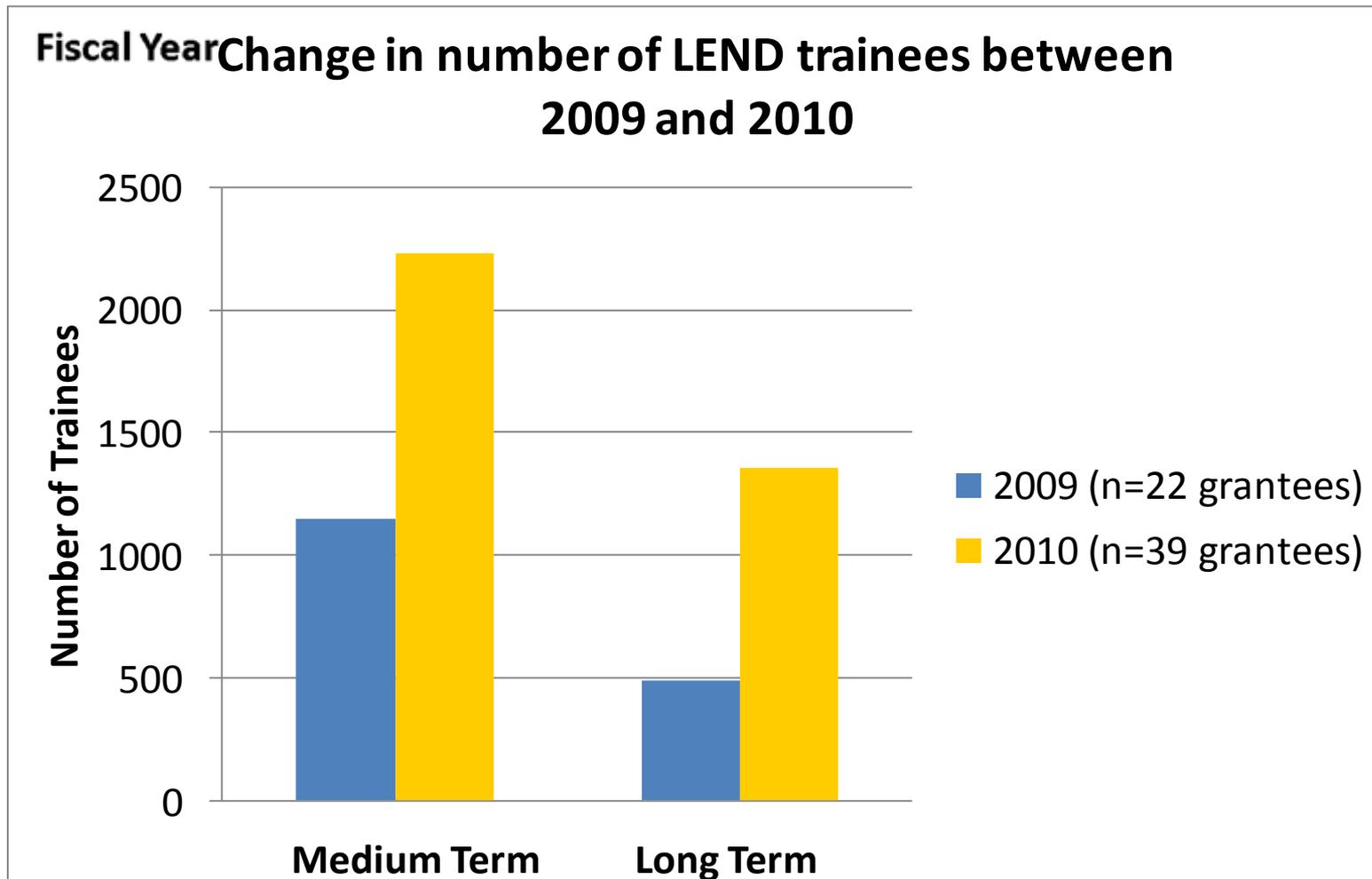
Funding, FY 2012

Autism Intervention Research, \$9.7 m

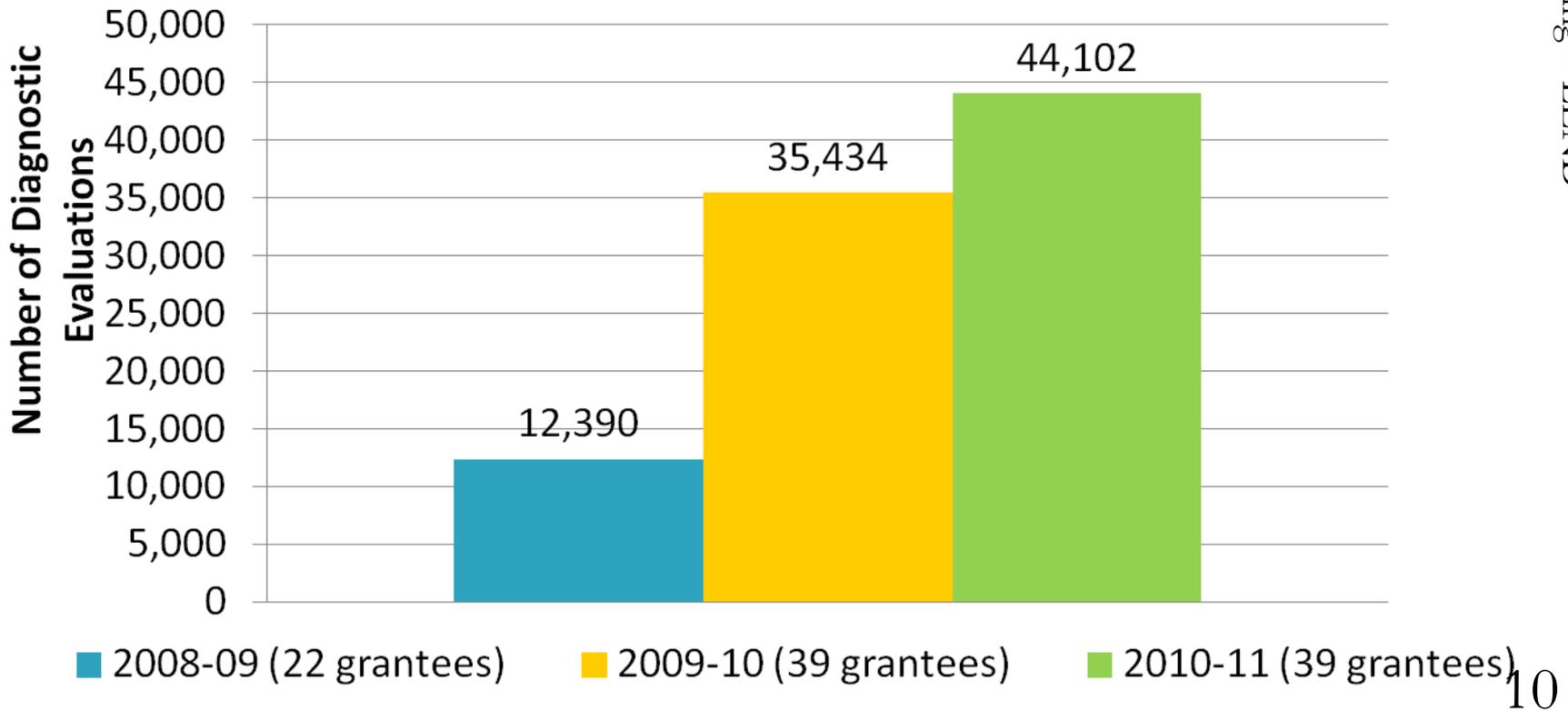
Interdisciplinary Training, \$30.8 m

State Demonstration, \$3.3 m

Training: More Professionals in the Pipeline



Evidence of Progress: Increased Number of Diagnostic Evaluations





www.mchb.hrsa.gov/autism

MCH Home

Grants

Programs

Res

[MCH Home](#) > [Programs](#)

Funded Activities

[Combating Autism and Other Developmental Disabilities Home](#)

[Training for Professionals](#)

[State Demonstrations and Policy](#)

[Research](#)

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Combating Autism and Other Developmental Disabilities

Combating Autism Act

This \$48 million effort, HRSA's implementation of the Combating Autism Act of 2006, addresses some of the most urgent issues affecting people with autism and their families. A national evaluation also will be conducted to report to Congress on progress related to Autism Spectrum Disorders and other developmental disabilities.

The evaluation will contribute to the U.S. Department of Health and Human Services Secretary's Report to Congress on progress related to Autism Spectrum Disorders and other developmental disabilities as required by the Combating Autism Act of 2006.

- Increasing awareness
- Reducing barriers to screening and diagnosis;
- Supporting research on evidence-based interventions for children and adolescents with Autism Spectrum Disorders or other developmental disabilities;
- Promoting evidence-based guideline development for



About Autism

[HHS Autism Information](#) (U.S. Department of Health and Human Services)

[Autism Spectrum Disorders](#) (National Institutes of Health)

[Autism Research at NICHB](#) (National Institutes of Health)

[Autism Information Center](#) (Centers for Disease Control and Prevention)

[Act Early Ambassadors](#) (Health Resources and Services Administration and Centers for Disease Control and Prevention)

Combating Autism Act

[Combating Autism Act. Public Law 109-416](#) (PDF - 49 KB)

[Interagency Autism Coordinating Committee](#) (U.S. Department of Health



CAAI Research Efforts



- \$44M awarded in research grants for CAAI (2008 – 2012) :
 - 3 Research Networks
 - 25 R40 Investigator-initiated Grants



Research Networks



- **Autism Intervention Research Network on Behavioral Health (AIR-B)**
- **Autism Intervention Research Network on Physical Health (AIR-P)**
- **Developmental and Behavioral Pediatrics (DBPnet)**



An Introduction to the Combating Autism Act Initiative (CAAI): Training Programs

- Two training programs fall under CAAI
 - Leadership Education in Developmental Behavioral Pediatrics (DBP)
 - Leadership Education in Neurodevelopmental and Related Disabilities (LEND)
- Both are long-term training programs (>300 hours) in large part, though they include training medium and short term trainees as well



Leadership Education in Developmental Behavioral Pediatrics (DBP)

- 10 MCHB-funded DBP programs around the country that focus on autism and related disabilities
- Also other DBP programs throughout the country that are not funded by the bureau
- Nation-wide shortage of DBP-trained physicians to treat those with ASD and other developmental disabilities (DD)

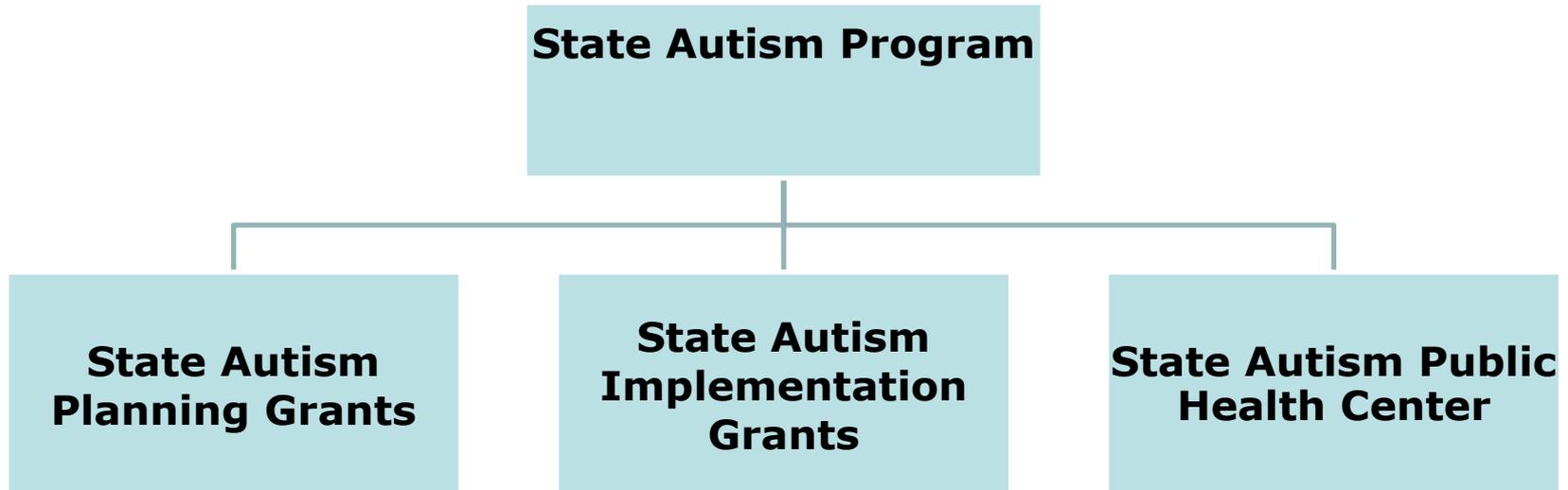


Leadership Education in Neurodevelopmental and Related Disabilities (LEND)

- 43 LEND programs around the country in urban and rural areas
- 6 new LEND programs as a result of recent grant competition
- All LENDs must have a focus on developmental disabilities, and more recently with the passing of CAAI, a focus on ASD



State Autism Implementation Programs





State Autism Implementation Programs



Number of new Grantees (22)	Years Funded	States
6	2008-2011	AK, WA, IL, MO, UT, WI
3	2009-2011	NM, NY, RI
4	2010-2013	VT, ME, HI, NJ
5	2011-2014	CO, OH, ND, MS, CT
4	2011-2013	MD, TN, DE, GA (State Planning Grants)



Healthy People (HP) 2020 Objectives will reflect advances by CAAI Investments

Multiple HP 2020 objectives relate to the health of children and adults with disabilities.

The Health and Disabilities section includes objectives which highlight areas for improvement and opportunities for people with disabilities to:

- Be included in public health activities.
- Receive well-timed interventions and services.
- Interact with their environment without barriers.
- Participate in everyday life activities.



Healthy People 2020



MICH–29: Increase the proportion of young children with an Autism Spectrum Disorder (ASD) and other developmental delays who are screened, evaluated, and enrolled in early intervention services in a timely manner.



Healthy People 2020



- MICH–29.1** Increase the proportion of young children who are **screened** for an Autism Spectrum Disorder (ASD) and other developmental delays by 24 months of age.
- MICH–29.2** Increase the proportion of children with an ASD with a first **evaluation** by 36 months of age.
- MICH–29.3** Increase the proportion of children with an ASD **enrolled in special services** by 48 months of age.
- MICH–29.4 (Developmental)** Increase the proportion of children with a developmental delay with a first evaluation by 36 months of age.



Healthy People (HP) 2020 Objectives will reflect advances by CAAI Investments

- To the Autism specific HP 2020 Objective see: <http://www.healthypeople.gov/2020/topicsobjectives2020/objectiveslist.aspx?topicid=26>
- For those related to autism in the Health and Disability section see: <http://www.healthypeople.gov/2020/topicsobjectives2020/overview.aspx?topicid=9>

Presentation



Zachary Warren, Ph.D.

Vanderbilt University

Departments of Pediatrics & Psychiatry

Vanderbilt Kennedy Center / TRIAD



The Diagnosis of Autism in Community Pediatric Settings: Does Advanced Training Facilitate Practice Change?

Zachary Warren, Ph.D.

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Departments of Pediatrics & Psychiatry
Vanderbilt Kennedy Center / TRIAD

Wendy L. Stone, Ph.D.

University of Washington
Department of Psychology

Quentin Humberd, M.D., FAAP

Ft. Campbell / Blanchfield Army Community Hospital
Chief, Exceptional Family Member Program

Project Description

- AAP Guidelines for 18 & 24 month ASD screening.
- How do we translate screening into efficient, effective diagnosis/treatment?
 - Ideally: Time sensitive, comprehensive, expert multidisciplinary evaluations
 - Reality: Long waits, familial distress, limited services, identification failures
- AAP guidelines do call for immediate referral to local Birth-to-Three/Part C systems, but often a specific ASD diagnosis is *required* to access high intensity specialized intervention.
 - Other considerations: Insurance, Family Understanding/Autonomy
- This initiative represents a collaboration between the TN chapter of the AAP, the Birth-to-Three/Part-C system, Vanderbilt's LEND program, & Vanderbilt Children's Hospital regional diagnostic center.
- The statewide training was explicitly designed with the goal of providing community pediatricians training in a methodology for accurate diagnostic identification of ASD within their own practice setting subsequent to screening.



Target Population

- Community pediatric providers
- Create a training framework for performing ASD diagnostic evaluations within community based pediatric practices that can:
 - *Reduce waits between screening and diagnosis/service delivery*
 - *Accurately identify children with/out ASD*
 - *Link children with appropriate early intervention services*
 - *Meet time demands / restrictions*
 - *Be adequately reimbursed*
- Underserved, rural, mega-practices, specialty clinics, comprehensive care programs, primary care & specialty settings
- Community partners / early intervention system

Tools & Training

- 1.5 day CME event trainings
 - Administration and scoring of MCHAT and STAT
 - Developmentally sensitive interviewing
 - Diagnostic decision making / DSM framework
 - Explaining results to families
 - Coding/reimbursement
 - Birth-to-Three/Part-C Involvement
- Fidelity procedures
- Case confirmation and consultation

Benefits/Successes

27 providers across TN:

- 10 large, 8 solo/small, 4 med centers, 3 underserved, 2 mil. Hospitals
- 20 Peds, 3 DBPs, 3 PNPs, 1 Neurologist
- 17.6 years in practice ($SD = 12.44$; range = 2–39 years)

Practice change on average 1.5 years following training:

- 82% increase in children identified within practice
- 75% within practice assessment following screen (25% pre)
- 68% using STAT (0% pre)
- Increased comfort and appropriateness of within practice assessment
 - 92% felt appropriate diagnosis within practice

Diagnostic accuracy (Practitioner vs. Blinded Comprehensive Psych. Eval):

- Pilot: 71%, forced choice, unstructured eval (Warren, et al., *JDBP*, 2009)
- Replication: Confirmation 86-93%, forced-unforced models

Partner Trainings: Children's Hospital Philadelphia; OUHSC; SC Act Early/AUCD; MUSC, Greenville Hospital System; IUPUI (pending); Society for Developmental and Behavioral Pediatrics

Reduction in waits within host center:

- Collaborative synergy

Challenges

Should we do this?

- Provider buy-in, system buy-in
- Realities of access

Family input

- Would you like to talk to your pediatrician or see a specialist?

Who can and should do this?

- Generalization / misclassification

The scope of the challenge:

- 1/150 to 1/88 during project timeframe
- Provider change with population level impact?
- Diagnosis only a starting point

Embedding training within medical education & systems of care

Value & impact: Expediting effective diagnosis and treatment?

Acknowledgements

Program Support:

Vanderbilt LEND: Drs. Urbano & Reimshisel (MCHB Grant No. T73MC00050)

Vanderbilt Kennedy Center / EKS IDDRC (NICHD P30HD15052)

TNAAP EPSDT TNCare Grant

Collaborators:

Quentin Humberd

Wendy Stone

Amy Swanson

Alison Vehorn

Elizabeth Dohrmann

Supporting organizations:

TNAAP

Tennessee Early Intervention System

VKC – TRIAD

UT-Memphis / Boling Center

Our participating pediatricians and practices

Presentation



Laura J McGuinn, MD

Associate Professor of Pediatrics

University of Oklahoma Health Sciences Center



Training local pediatricians to do more intensive screening & identification in the office

Laura McGuinn, MD, FAAP

Associate Professor of Pediatrics
OUHSC Dept of Pediatrics Section on DBP, Child Study Center

Mark Wolraich, MD, FAAP

Shaun Walters/Children's Medical Research Institute Endowed
Professor of Pediatrics and DBP Section Director
OUHSC Dept of Pediatrics Section on DBP, Child Study Center

Thomas Lock, MD, FAAP

Professor of Pediatrics
Indiana University, Riley Child Development Center

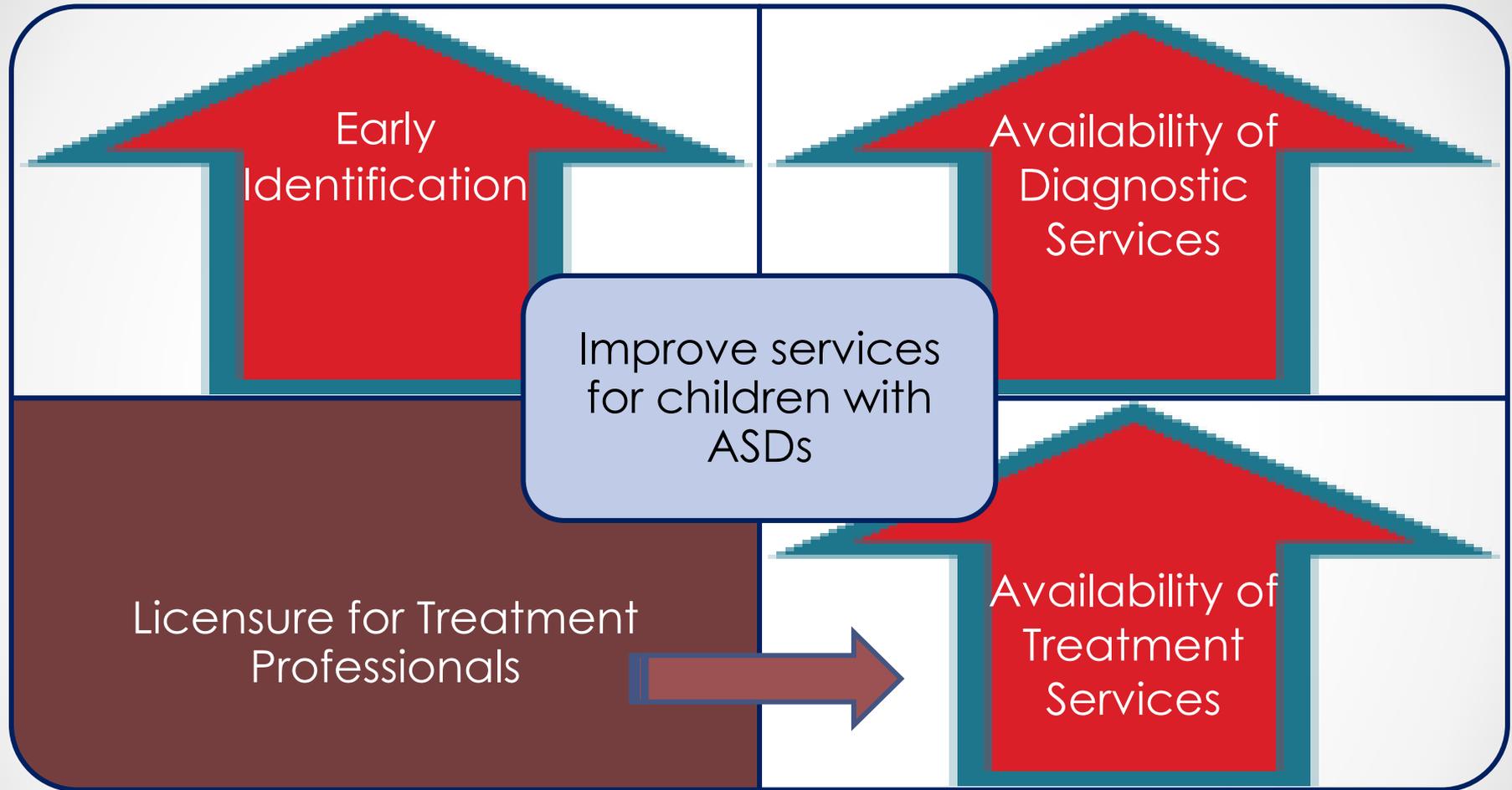


Project Description: OK Autism Workforce Initiative

- **Goal:** ↑ DX & TX services for individuals w/ ASDs
- **Funding:** OK Senate Bill 135 (Nov '09 x 3y) and LEND
 - Requested ~500K....\$243K was appropriated
- **Strategy:** ↑ service capacity NOT insurance coverage
 - State budget \$ for ASD svcs unused...families couldn't find any
 - SO...Even if insurance mandates passed, no svcs available
- **PCP Training:** Contract w/ Vanderbilt for STAT-MD
 - Mar 2010, Oct 2010, Oct 2011...NEXT: Oct 2012
 - Learning collaboratives x2 plus D2L online listserve



Project Description: OK Autism Workforce Initiative



Target Population

- Initially targeted:
 - Pediatricians and Family Physician PCPs
- Then:
 - NPs/PAs
 - Psychologists/Neuropsychologists
 - Neonatologists
 - Pediatric and Med-Peds Residents
- Recruitment based on PCPs in counties with:
 - Sooner SUCCESS Care Coordination Program
 - Early Foundations (Model ASD Early Intervention Program)
- Community Partners

Tools & Training

- STAT-MD training as described by Dr. Warren
- Learning Collaborative (in-person and D2L online)
 - Didactic talks/discussions
 - Intro to psychopharmacology
 - Sleep problems
 - Genetic Testing in Autism
 - Clinical Implementation/Challenges
 - Review STAT/history process
 - Bring difficult cases to discuss with group
 - Interdisciplinary Development
 - School teams
 - Community OT/ST/behavior therapists
 - Family partners from practices



Benefits/Successes

30 providers across OK (19 PCPs):

- Settings: 12 solo/small (1 employed), 3 med ctrs (2 subspec clinics, 1 NICU f/u, 1 Rehab Ctr), 1 underserved
- Provider Specialty: 12 Peds, 3 PNPs, 1 PA, 3 FPs, 2 peds residents, 3 DBPs, 2 DBP fellows, 2 Neonatologists, 2 Neuropsychologists
- In OK: ~450 MD Pediatricians (PCP, subspecialty, residents) ~92K kids (if 1:88 ASD = ~1045 ASD in OK) Each of the 30 trained providers would need to see 34 children/yr if equally divided per STAT trainee

Practice change on average 1.5 years following training (Survey N=19):

- xx% within practice assessment following screen (xx% pre)
- 67% using STAT (0% pre)
- Increased comfort and appropriateness of within practice assessment
 - 100% somewhat (86%) or very (14%) confident (38% pre)
 - xx% felt appropriate diagnosis within practice

Diagnostic accuracy (Practitioner vs. Blinded Comprehensive Psych. Eval):

- 5 cases have been evaluated with 80% agreement (4/5)

TBD: Child access to intervention and other services; Family satisfaction



Challenges (per Participant Survey)

- Problems with STAT Implementation
 - Time in practice overall
 - Longer appointment times for STAT
 - Need more practice using STAT
 - Need help getting the validation done
 - Need more scoring booklets
 - Reimbursement for longer appointments for STAT
- Desire for Future:
 - General education on autism
 - Specific diagnostic evaluation training (e.g. like the ADOS)
 - Training on instruments to use with older children (i.e. for kids too old for STAT)

Panel Discussion



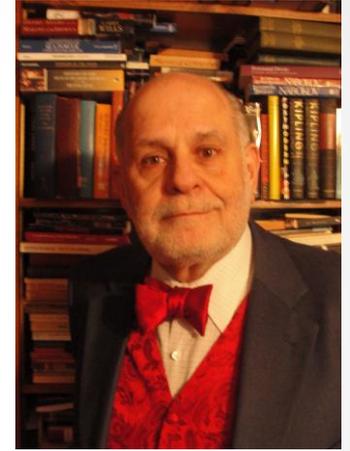
Zachary
Warren



Laura
McGuinn



Bruno
Anthony



Pasquale J.
Accardo



Presentation



Bruno Anthony, Ph.D.

Professor & Director of Research & Evaluation

Georgetown University



Improved Early Identification of Autism in Latino Children

BRUNO ANTHONY, PhD
MATTHEW BIEL, MD, MSc
DIANE JACOBSTEIN, PhD
ISABELLA LORENZO-HUBERT, MEd
KERI LINAS, PH.D/PSY.D
SANDRA SOTO, MPH, RN
Georgetown University

LUIS PADILLA, MD
MARK MINIER, MD
Unity Health Care



Project Description

- Disparities in rates of diagnosis of ASD in Latino vs. non-Latino children and delays in access to services.
- Evidence-based screening tools have facilitated increased rates of ASD diagnosis but often not used in primary care.
- Overall goals: Increase number of Latino children (1) screened for autism and developmental delay with an evidence-based measure, (2) referred for evaluation with reduced delay; and (3) receiving services.
- Accomplish these goals through:
 - Increasing awareness of developmental milestones among Latino parents of young children
 - An evidence-based screening program (Supported Screening) adapted specifically to the needs of Latino families
 - A family navigation program to link Latino families with providers for children with ASD



Target Population

- Families with children between the ages of 18 and 30 months whose primary pediatric care is provided by the Upper Cardozo Health Center of Unity Health Care of DC.
 - Largest clinical site for Unity Health Care
 - 17,000 pediatrics visits/year
 - Primarily Latino families
 - Large percentage of parents are monolingual Spanish speaking, primarily from Central America
 - Central location in D.C.



Tools

- Screening - M-CHAT – Adapted to facilitate effective screening
 - Oral administration
 - Combining screen and follow-up protocol
 - Including explanations for 3 questions identified through cognitive testing
- Training and coaching
 - Training for medical providers
 - Autism and importance of early detection
 - M-CHAT and screening practices
 - Strategies around effective referral for services
 - Engaging families and forming partnerships
 - Training for medical and administrative staff
 - Autism and screening
 - 1:1 coaching for providers
- Family support and navigation
 - Bilingual and bicultural parent with lived experience
 - Ongoing consultation with families identifying with concerns and linkage to community resources
 - Resource for all families



Benefits/Successes

- Adapted M-CHAT Screening
 - Increase in screenings from pre-Supported Screening levels
 - Spread across Unity sites adaptation
 - Ability to track screens and referrals through Unity EMR
- Training and Collaborative Coaching
 - Five one-hour training sessions for providers and two one hour training session with medical and administrative staff
 - Well-attended with high satisfaction
 - Large change in knowledge base (particularly screening process)
 - Discussion re: cultural issues helpful
- Family Support and Navigation
 - Administration M-CHAT, investigate positive screens, follow up on confusing questions
 - Collaboration with medical providers to deliver results of screen to families
 - Family support in connecting with evaluation services
- Increased awareness of developmental milestones among Latino parents of young children
 - “Developmental fairs” and Charlas
 - Positive communication, interactions between families and primary care staff
 - Referrals to navigators from families outside target population

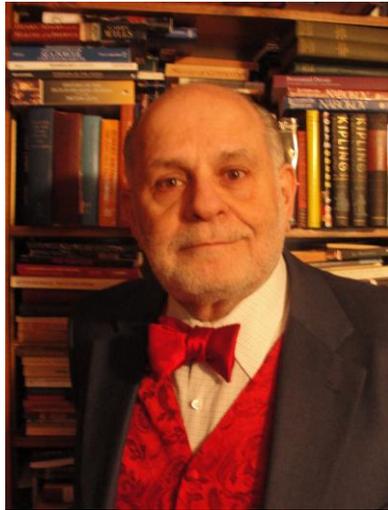


Challenges

- Research vs program development
- Administration of the screening protocol
 - Need for oral administration
 - Difficult for pediatricians/nurse practitioners to complete
 - Cultural barriers
- Logistics
 - Access to records
 - Communication between navigators and providers
 - Linkages with early intervention
- Sustainability
 - Alternate models for screening



Presentation



Pasquale J. Accardo, M.D.

James H. Franklin Professor of Developmental Research in
Pediatrics, VCU Child Development Clinic
Virginia Commonwealth University



Physical Markers for Autism

Pasquale Accardo, M.D.

James H. Franklin Professor of Developmental Research in
Pediatrics

Virginia Commonwealth University

Children's Hospital of Richmond Child Development Clinic
Richmond, Virginia



Project Description

Before 'screening' specifically for autism, are there medical markers (things that a pediatrician routinely observes in all children) that can increase one's suspicion for the presence of autism?

- Expressive vocabulary at age 2 years
- Restricted diet [nutrition]
- Growth in head circumference [morphometrics]
- Toe walking [motor development]



Head Circumference

- Using Nellhaus charts more microcephaly than others
- Using CDC charts
 - 17% of ASD children had $OFC \geq +2SD$
- Using Rollins et al
 - 19% of ASD children had $OFC > +2SD$



Toe Walking in Autism

- 62.9% (Accardo and Whitman, 1989)
- 19% (Ming, Brimacombe, and Wagner, 2007)
- 20.6% (Barrow, Jaworski and Accardo, 2011)



Benefits

- Sensitizing pediatricians to the implications of things they are already doing
- And are comfortable with
- These markers would typically be obvious prior to the use of the M-CHAT at 18 months



Challenges

- Many children with autism have average OFCs and do not toe walk.
- Therefore, using these physical markers does not absolve from the use routine autism screening measures such as the M-CHAT



Panel Discussion



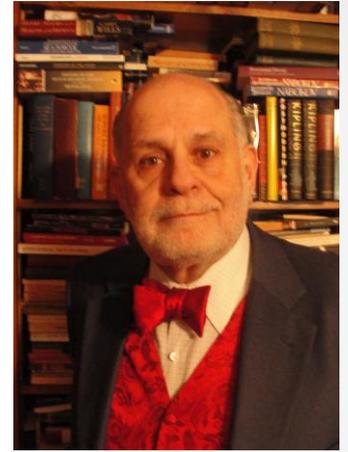
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Bruno
Anthony



Pasquale J.
Accardo



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The moderators will read the
questions



DSM-5 Information

History and Background:

The American Psychiatric Association (APA) has proposed new diagnostic criteria for autism to be included in the 5th edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5). The proposal would create a new diagnostic category called autism spectrum disorder which would incorporate several previously separate diagnoses including autistic disorder, Asperger's disorder, childhood disintegrative disorder and pervasive developmental disorder not otherwise specified.. The recommended changes to the diagnostic criteria came from the DSM-5 Neurodevelopmental Work Group, a group of experts in the field. The criteria are currently being tested in field trials in order to provide more information about their validity. The release of the final, approved DSM-5 is expected in May 2013. The committee is currently accepting Final Public Comments on the proposed changes until June 15th, 2012.

For more information & to provide comments go to the DSM-5 website www.dsm5.org

Information from autism and disability organizations:

Association of University Centers on Disabilities

http://www.aucd.org/template/news.cfm?news_id=7967&parent=16&parent_title=Home&url=/template/index.cfm?

Autistic Self Advocacy Network

<http://autisticadvocacy.org/2012/06/asan-policy-brief-how-will-dsm-5-impact-services/>

Autism Society

<http://www.autism-society.org/news/an-update-on-the-dsm-5.html>

Autism Speaks

<http://www.autismspeaks.org/blog/2012/05/21/geris-dsm-5-update-imfar>



The Combating Autism Act Initiative

Webinar Series

The CAAI Webinar series, "Research to Practice" will showcase successes of CAAI grantees, connect attendees with other CAAI grantees, and inform each other of activities happening within the initiative. The series will run from April through August 2012.

This webinar series replaces the annual face-to-face conference for CAAI.

Upcoming Webinars from the [CAAI Webinar Series](#):

- Innovative Interventions for Children and Youth with Autism Spectrum Disorders
July 17, 2012 3:30 PM-5:00 PM Eastern
- Building Systems of Care for Children, and Youth with ASD through the CAAI training, research and demonstration grants
August 22, 2012 2:00 PM-3:30 PM Eastern



For more information go to:

http://www.aucd.org/template/event.cfm?event_id=2847&id=0