

Autism Intervention Research Network on Physical Conditions: Research Report

CAAI Meeting
December 7, 2009

James M. Perrin, MD
Director, AIR-P Clinical Coordinating Center



Autism Treatment Network AIR-P Research

- Funded by a grant from the Maternal and Child Health Bureau, Health Resources and Services Administration
- AIR-P goals include
 - Conducting research in physical health aspects of autism spectrum disorders (ASD)
 - Developing evidence-based guidelines for care in ASD
 - Providing community education regarding ASD
- The AIR-P project utilizes the infrastructure of the ATN to carry out its projects

ATN Mission

- Expanding the number of high-quality multidisciplinary clinical sites providing comprehensive evaluation and care for children and youth with ASD
- Develop evidence-based practice and treatment guidelines to improve medical care for families and to leverage insurance reimbursement for autism treatments
- Use of a data registry of children receiving ongoing care in participating sites to compare clinical efforts in a search for best practices for children with ASD
- Develop multisite and multidisciplinary research to improve treatment of medical conditions among children with ASD

Autism Treatment Network

- 14 sites in US and Canada
- Criteria for participation
 - Multidisciplinary team care
 - Use ATN clinical evaluation
 - Enter at least 100 subjects per year into registry
 - Participate in ATN committees (e.g., operations, clinical subspecialties)
- Key collaborators
 - Autism Speaks
 - Clinical coordinating center - MGHFC
 - EMMES Corporation
 - National Initiative for Children's Healthcare Quality

2008-2009 Research Activities

- AIR-P Research
 - Nutrition launched
 - Sleep launched
- AIR-P Investigators Meeting (April 2009)
- AIR-P Steering Committee Meeting (May 2009)
- AIR-P Network RFA (June 2009) - 16 applications
 - Two Level 1 Projects funded
 - Two Level 2 Projects funded

ATN/AIR-P Scientific Review Committee

- Representative from each AIR-P site with substantial research experience and external funding
- Additional external reviewers in diverse aspects of autism research and methodology

“Diet and Nutrition in Children with Autism Spectrum Disorders: An ATN Study”

- Lead PI: Susan Hyman, MD
- Lead Site: University of Rochester
- Collaborators: Jill James, Arkansas
Cindy Molloy, Cincinnati
Ann Reynolds, Colorado
Cindy Johnson, Pittsburgh
- Project Period: 09/01/2009 - 08/31/2011
- Study Aims:
 - Assess nutritional intake and dietary patterns in a large and well characterized cohort of children with ASD
 - Assess excess intake with nutritional supplementation
 - Compare iron status and vitamin D levels to dietary intake
 - Describe relationship of diet and nutrition to physical symptoms related to sleep and GI function

“Parent-Based Sleep Education Program for Children with Autism Spectrum Disorders”

- Lead PI: Beth Malow, MD
- Lead Site: Vanderbilt University Medical Center
- Collaborators: Cindy Molloy, Cincinnati
Ann Reynolds, Colorado
Wendy Roberts, Toronto
- Project Period: 03/01/2009 - 02/28/2012
- Study aims:
 - To determine the efficacy of a sleep education pamphlet compared to no sleep education in children with ASD
 - To compare two nurse-led sleep interventions in children with ASD
 - To conduct a larger scale RCT comparing the more effective intervention developed in Phase 1, with the control intervention (sleep education pamphlet)
 - To determine if the intervention improves sleep latency, as measured by actigraphy

“Defining the Relation of Sleep Disturbance in Autism Spectrum Disorder to Psychiatric and Behavioral Co-morbidities”

- Lead PI: Suzanne Goldman, PhD
- Lead Site: Vanderbilt University Medical Center
- Project Period: 10/01/2009 - 09/30/2010
- Study aims:
 - To define the psychiatric and behavioral co-morbidities associated with disordered sleep in children with ASD

“Bone Mineral Density in Children with Autism Spectrum Disorders”

- Lead PI: Ann Neumeyer, MD
- Lead Site: MGH/LADDERS/Lurie Center
- Collaborators: Cindy Molloy, Cincinnati
Sue McGrew, Vanderbilt
- Project Period: 12/01/2009 - 11/30/2010 *(projected)*
- Study aims:
 - To investigate the degree to which bone mineral density is impaired in children with autism and to explore specific additional risk factors

“Markers of Iron Status and Metabolism in Children with ASD”

- Lead PI: Ann Reynolds, MD
- Lead Site: University of Colorado
- Collaborators: AIR-P Nutrition Sites
(Arkansas, Cincinnati, Pittsburgh, Rochester)
- Project Period: 12/01/2009 - 11/30/2010 *(projected)*
- Study aims:
 - To evaluate iron intake, iron status and associated sleep disorders in a large, well characterized sample of children with ASD

“Prevalence of Creatine Deficiency Syndromes and Genetic Variability in Creatine Metabolism in Children with ASD: A Pilot Study”

- Lead PIs: Andreas Schulze, MD, PhD ; Alvin Loh, MD
- Lead Site: University of Toronto
- Collaborators: Margaret Bauman, MGH/LADDERS/Lurie Center
Ann Tsai, University of Colorado
- Project Period: 01/01/2010 - 12/31/2010 *(projected)*
- Study aims:
 - To identify the prevalence of creatine deficiency syndromes in children with autism spectrum disorder
 - To treat individuals with ASD and a specific creatine deficiency syndrome with a defined protocol
 - To compare the effects of creatine supplementation for children with ASD with low urinary creatine excretion vs children with ASD with normal urinary creatine excretion

Recent ATN Abstracts from Registry Review

- *"Use of Psychotropic Medications in Autism Spectrum Disorders"*
- *"Complementary and Alternative Medicine Use in Children with Autism Spectrum Disorders"*
- *"Factors Associated with Sleep Problems in Children with Autism Spectrum Disorders"*
- *"Association of Parent Reported Behavior Problems, Sleep Problems and Gastrointestinal Problems in Children with Autism Spectrum Disorders"*

Proposals & Areas of Interest

- Genetics / Biobanking
 - *Critical theme for the ATN!*
- Gastrointestinal
 - GERD and Sleep
 - Areas from AS/NASPGHAN/AAP Symposium
- Neurology
 - EEG/epilepsy/neuroimaging
- Metabolic
 - Lead levels in children with ASD
 - Smith-Lemli-Opitz Syndrome and cholesterol levels in children with ASD
- Psychopharmacology
- Co-existing conditions
 - Tuberos Sclerosis and fragile X
 - ADHD and other co-existing conditions
- Pain in children with ASD

Items for the Future

- New AIR-P internal RFA early in 2010
- CAAI renewal
- Expanding science in the ATN and AIR-P Network
 - Strategic scientific advisors
 - Systematic search for investigators to partner with ATN and AIR-P in key areas
 - Identifying new sources of funding (NIH and others)

AIR-P Guideline and Dissemination Updates

CAAI Meeting

December 7, 2009

Daniel Coury, MD

Medical Director, AIR-P Clinical Coordinating Center

Clinical Guidelines Background and Goal

- Background - While there are guidelines for screening and evaluation of autism spectrum disorders (ASD), there are no clinical guidelines for medical care of children with ASD
- Goal - develop and disseminate medical guidelines to improve treatment, care and quality of life for children with ASD

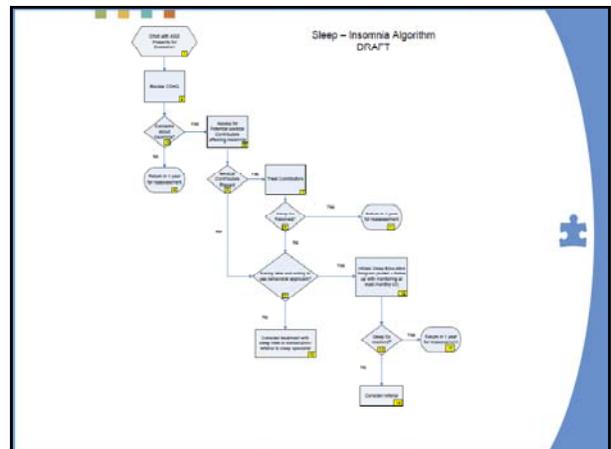
Algorithms and Toolkits

With little evidence in the literature, we are developing guidelines that are more expert consensus than evidence-based. These have focused on the most common concerns:

- Insomnia/night-waking
- Constipation
- EEG
- Behavioral
- Medication monitoring

Insomnia/ night-waking algorithm

- Developed by ATN sleep committee led by Beth Malow MD, with support of NICHQ
- Pilot implementation
 - Initial sites - Kaiser and Missouri
 - Expanding to Baylor and OHSU
- Toolkit
 - Using behavioral pamphlet covering bedtime routine strategies and worksheet, methods for teaching routines, and the bedtime pass method



Under Development Behavioral Treatments Toolkit

- Currently being developed by Behavioral Scientist Committee
 - Intended to augment AAP toolkit
 - Focus areas identified by Committee
 - Toileting
 - ABA (basics for parents)
 - Behavior management basics
 - Feeding/diet
 - Adult Transition



Under Development Medication Monitoring Algorithm

- Currently being developed by Psychopharmacology subcommittee
- Focus on monitoring side effects of anti-psychotic medications
- Will begin implementation and measurement at sites in early 2010 (who is on medication, growth parameters, metabolic measures, adverse effects)



QUESTIONS



Autism Intervention Research for Behavioral Health Network

Connie Kasari, PhD Bryan King Rebecca Landa, PhD Cathy Lord Amy Wetherby



AIR-B Activities

- Research Protocols
- Guideline Development
- Dissemination and Tool Development

Research Protocols

- Protocol 1
 - Joint Engagement Intervention for Parents and Young Children with Autism
- Protocol 2
 - Social Skills Interventions at School
- Protocol 3
 - Social Skills via Web Based Delivery

Common Features of Protocols

- All focused on underserved or under-represented populations
- Intervention focus on core deficits in autism
- Interventions carried out in natural environments
- Multi-site studies involving web-based online manuals for training purposes

Protocol 1: Joint Engagement Intervention

- **Problem:** *Children from low income environments have much less access to evidence based interventions*
- RCT comparing a parent education model to a parent mediated intervention
- Children between 2 and 5 years of age (n=200)
- Interventions 1x/wk for 12 weeks in the home
- Focus on joint attention/joint engagement across everyday activities and effects on social communication abilities

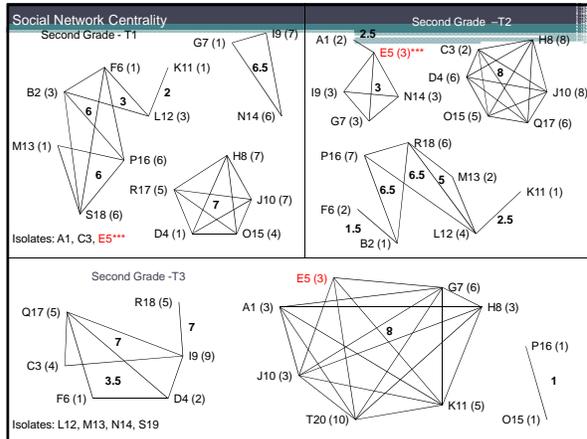
Protocol 2: Social skills at School

- **Problem:** *Children included in general education are often without services, and have need for social skills interventions*
- High functioning children with ASD who are fully included at school in elementary schools (under-represented) (n=150)
- ENGAGE group involves typical peers and involvement on the playground
- SKILLS group is standard practice

ONLINE TREATMENT MANUAL: Peer Engagement Group (PEG)

- Secure online treatment manual
- Accessible across sites
- Regularly updated
- Online manual includes:
 - Description of PEG treatment
 - Video Samples
 - Description of Measures
 - Troubleshooting and FAQ Sections

Home Introduction Engagement Status Setting Up Session Overview
 Sample Session Start Your Group Restroom Lunch Conversation
 Play a Game Tell a Story Transitions Home Materials/Behavior
 Measures Conclusion References FAQ Collaborators



Protocol 3: Web based social skills

- **Problem:** *Lack of available services for rural families*
- Web based social skills intervention
- Focus on rural children with limited access to evidence based interventions

Protocol 3: Web-skills training



Leverage of AIR-B Collaboration

- ARRA funds
- Protocol 4: Teen Engage vs. Skills Groups
 - High school students
 - Under-served population of children
- Lead is UW-Felice Orlich
 - UMACC
 - UCLA

Guideline Development

- RAND has lead on guideline development
- Literature searches complete
- Data abstraction and analyses in progress
- Evidence report due at year's end
- Face to face guideline development meeting in Spring 2010

AIR-B Dissemination

Public Website (ASDweb .org)

Online Knowledgebase

Web-skills training

The diagram illustrates the dissemination process. On the left is the 'Public Website (ASDweb .org)' with a header for 'UCLA UCLA Autism Intervention Research Network on School-Age Youth'. In the top right is the 'Online Knowledgebase' titled 'PhenWiki: An Online Collaborative Resource for Phenotypic Association'. In the bottom right is a 'BrainFest' event page titled 'Social Skills for Planet Earth' with a cartoon astronaut. Two blue arrows point from the public website to the online knowledgebase, and another blue arrow points from the online knowledgebase to the BrainFest event page.

Collaboration

- UCLA
 - Connie Kasari
 - Jim McCracken
 - Fred Frankel
 - Fred Saab
 - Catherine Sugar-SYSTAT
 - Jill Locke
 - Mark Kretzmann
 - Kathy Lawton
 - Sara Levitt
- FSU
 - Amy Wetherby
 - Renee Holland
- KKI
 - Rebecca Landa
 - Brian Freedman
 - Rondalyn Whitney
 - Tyson Barker
- RAND
 - Margaret Maglione
- UMACC
 - Catherine Lord
 - Constanza Columbi
- UW
 - Bryan King
 - Felice Orlich



MCH Research Program

Health Resources and Services Administration
Maternal and Child Health Bureau

R40 Autism Intervention Research

- Initiated in 2009 with additional funding through the Combating Autism Act of 2006
- Supports research on evidence-based practices for interventions to improve the health and well-being of children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities
- Consistent with HRSA's mission, projects address the unique needs of underserved populations
- Includes both 2-year research and 1-year secondary data analysis studies (SDAS).
- 5 R40 2-year projects awarded
- 2 SDAS 1-year projects awarded



MCH Research Program

Health Resources and Services Administration
Maternal and Child Health Bureau

R40 Autism Intervention Research Grantees

- University of Colorado Denver
- Kennedy Krieger Institute, Inc.
- Boston Medical Center
- University of New Hampshire
- Brandeis University



MCH Research Program

Health Resources and Services Administration
Maternal and Child Health Bureau

Tele-health Delivery of a Family-Focused Intervention to Reduce Anxiety in Youth with Autism Spectrum Disorders in Rural Colorado

Grantee: University of Colorado at Denver (JFK Partners)

PI: Susan Hepburn, Ph.D.

- Goals: Develop and evaluate use of interactive video conferencing to deliver a manualized coping skills program (Face Your Fears, Reaven et al, 2008) to families of children with ASD who live in rural Colorado
- Translational research focused on providing a promising, evidence-based intervention to an underserved population
 - Rural families in Colorado have limited access to skilled mental health care
 - Families of children with ASD have difficulties accessing specialized mental health supports
- Examine child & family outcomes as well as process measures of feasibility, cost, resources required, etc.



MCH Research Program

Health Resources and Services Administration
Maternal and Child Health Bureau

Parent-Mediated vs Center-Based Intervention for Toddlers with ASD: An RCT

Grantee: Kennedy Krieger Institute, Inc.

PI: Rebecca Landa, Ph.D.

- Compare two different early intervention approaches for minority and underserved toddlers with ASD: a home-based model emphasizing caregiver-mediated intervention and a combined model emphasizing center-based professional-mediated intervention
- There is a vacuum of empirically-based information to guide intervention decision-making for minority and underserved toddlers with ASD and results in disparity in services.
- Provide a rubric for empowering family members to contribute to the well-being of their children with ASD
- Provide an evidence-base for decisions about intervention approach.



MCH Research Program

Health Resources and Services Administration
Maternal and Child Health Bureau

Supporting the Well-Being of Families of Young Children with Autism Spectrum Disorders

Grantee: Boston Medical Center
PI: Emily Feinberg, Sc.D.

- Determine whether an evidenced-based empowerment strategy, Problem Solving Education (PSE), targeted to mothers of young children with autistic spectrum disorders (ASDs), promotes family well-being (decrease maternal depressive symptoms and parenting stress and improve maternal social functioning)
- Address a gap: the absence of adequately powered RCTs that examine the effects of interventions designed specifically to address depressive symptoms, parental stress, and social functioning among mothers of children with ASDs
- Support families during a critical juncture - time of diagnosis and during transition from EI to local school systems
- Test a participatory research model that builds the capacity of community-based settings to address maternal mental health



MCH Research Program

Health Resources and Services Administration
Maternal and Child Health Bureau

Family-Centered Transition Planning for Students with Autism Spectrum Disorders

Grantee: University of New Hampshire
PI: David Hagner, Ph.D.

- Test the effectiveness of a 3-component intervention on the transition readiness of young adults with autism spectrum disorders (ASD) using a randomized controlled trial in New Hampshire and Maine
- Dependent variables include level of career decision-making readiness, self-determination, student and family expectations for the future, adaptive behavior, and quality of the transition plan section of the student's IEP
- Include an individual on the autism spectrum as a member of the project team, to mentor youth in preparing for meetings and career exploration activities and serve as a model of successful transition
- Assist participants to receive adequate emotional support and plans to participate in meaningful social and recreational activities



MCH Research Program

Health Resources and Services Administration
Maternal and Child Health Bureau

Assessing a participant directed service system for low income children with ASD

Grantee: Brandeis University
PI: Marji Erickson Warfield, Ph.D.

- Evaluate the Massachusetts Medicaid Autism Waiver Program, a supportive services waiver program that uses a participant direction (PD) model to choose and manage services for young children with ASD and their families
- The only waiver program that serves low income children with ASD who are racially and ethnically diverse, provides both a range of home-based one-to-one interventions as well as support services, and utilizes participant direction as its only model of service delivery
- Generate new knowledge about the key components of the participant directed model; the interest and desire of families to take on the extensive tasks involved in participating; the treatments and supports families value and therefore choose for their child; and the relationship between families' use of participant direction and family well-being and child outcomes.



MCH Research Program

Health Resources and Services Administration
Maternal and Child Health Bureau

R40 Autism Intervention Secondary Data Analysis Studies (SDAS)

- University of North Carolina at Chapel Hill
- University of Massachusetts Boston



MCH Research Program

**Health Resources and Services Administration
Maternal and Child Health Bureau**

The Effectiveness of Special Education Services for Children with Autism: A National Longitudinal Study

Grantee: University of North Carolina at Chapel Hill
PI: Edward Michael Foster, Ph.D.

- Uses three longitudinal databases collected by the US Department of Education involving children in special education, each containing a sample of children with autism (Pre-Elementary Education Longitudinal Study (PEELS), Special Education Elementary Longitudinal Study (SEELS), National Longitudinal Transition Study-2 (NLTS2).
- Use these data and the latest tools of causal inference to assess the conditions and services (such as being educated in an inclusive setting) that improve the education of these children and youth.



MCH Research Program

**Health Resources and Services Administration
Maternal and Child Health Bureau**

Services and Outcomes for Transition Age Young Adults with Autism Spectrum Disorders: Secondary Analysis of the NLTS2 and RSA 911

Grantee: University of Massachusetts Boston
PI: John Butterworth, Ph.D.

- Inform the design of effective transition services and supports for young adults with ASD by identifying personal and programmatic factors that are related to postsecondary outcomes including postsecondary education, integrated employment, and independent living
- Project domains for analysis include transition outcomes, educational and vocational rehabilitation services and experiences, and personal and family characteristics
- Conduct descriptive and predictive analysis using the National Longitudinal Transition Study 2 and the Rehabilitation Services Administration 911 database

CAAI Research Activities

Funding through the Combating Autism Act Initiative (CAAI) supports several different research activities addressing a number of pressing issues in autism spectrum disorders. These include two autism intervention research networks and several other research activities.

Autism Intervention Research in Physical Health (AIR-P) Network and the Autism Treatment Network (ATN)

James Perrin, Daniel Coury

Established in 2005, the ATN is the nation's first network of hospitals and physicians dedicated to developing a model of comprehensive medical care for children and adolescents with autism. The ATN offers families care from doctors highly experienced in helping individuals with autism and providing treatment for associated conditions such as gastrointestinal and sleep disorders. ATN doctors are dedicated to finding better ways to manage the health of children with autism and sharing their increasing knowledge across the wider medical community. In particular, the ATN is dedicated to developing better ways to identify, manage and treat the physical health conditions of children with autism.

The AIR-P Network is a project funded by a cooperative agreement with the Maternal and Child Health Bureau, Health Resources and Services Administration. The AIR-P has goals of: (a) conducting research in physical health aspects of autism spectrum disorders (ASD), (b) developing evidence-based guidelines for care in ASD, and (c) providing community education regarding ASD. The AIR-P project utilizes the infrastructure of the ATN to carry out its projects. The AIR-P project thus has augmented the previous level of activity of the ATN in all of these areas.

AIR-P Guideline Development

Currently, no uniform set of clinical measures or data capture have been established to bridge the gap between research and clinical practice to enhance the treatment of autism. The AIR-P proposes to fill this gap by identifying and characterizing the various medical conditions observed in the ASD population and using this data to improve the treatment, care, and quality of life for individuals with ASD and their families. Data is captured by AIR-P sites through the ATN Registry. The goal of the ATN Registry is to provide data to inform the guideline development of medical care for children with autism.

Sleep, GI, and neurology subspecialists from the AIR-P sites have been working through 2009 to develop algorithms which are being piloted within the AIR-P and subsequently developed into formalized guidelines of care and disseminated to

physicians and other key stakeholders outside the AIR-P. AIR-P sites are currently piloting algorithms on the topics of constipation and insomnia and will soon begin piloting one on indications for conducting an EEG. Additional projects getting underway include guidelines for monitoring psychotropic medications and strategies for teaching behavioral management.

AIR-P Research Project Summary

The two initial AIR-P research studies focused on nutrition and on sleep problems.

- ***“Diet and Nutrition in Children with Autism Spectrum Disorders: An Autism Treatment Network Collaborative Study”***
Susan L. Hyman, M.D., of the University of Rochester is leading a research project aimed at evaluating the nutritional intake and dietary patterns of children and adolescents with autism spectrum disorder (ASD).
- ***“Development of a Parent-Based Sleep Education Program for Children with Autism Spectrum Disorder”***
Beth Malow, M.D., principal investigator for this three-phase, multi-site study, will compare two nurse-led parent education programs to see which approach is more effective in reducing the time it takes for children to fall asleep.

In September 2009 AIR-P initiated four additional research studies.

- ***“Defining the Relation of Sleep Disturbance in Autism Spectrum Disorder to Psychiatric and Behavioral Co-morbidities”***
Suzanne Goldman, Ph.D., of Vanderbilt University Medical Center aims to define the psychiatric and behavioral co-morbidities associated with disordered sleep in children with ASD.
- ***“Bone Mineral Density in Children with Autism Spectrum Disorders”***
Ann Neumeyer, M.D., from the MGH/LADDERS Clinic aims to investigate the degree to which bone mineral density is impaired in children with autism and to explore specific additional risk factors.
- ***“Prevalence of Creatine Deficiency Syndromes and Genetic Variability in Creatine Metabolism in Children with ASD: A Pilot Study”***
Andreas Schulze, M.D., from the University of Toronto is leading the first comprehensive population-based study looking at the prevalence of Creatine Deficiency Syndromes in autism in a diverse ethnic group, which could have implications for the diagnosis, treatment and possible improvement in the core symptoms of ASD.
- ***“Markers of Iron Status and Metabolism in Children with ASD”***
Ann Reynolds, M.D., of the University of Colorado aims to evaluate iron intake, iron status and associated sleep disorders in a large, well characterized sample of children with ASD.

The Autism Intervention Research on Behavioral Health (AIR-B) Network

A cooperative agreement was awarded in FY 2008 to the Regents of the University of California at Los Angeles. This research network will focus on the behavioral, mental, social, and/or cognitive health and well-being of children and adolescents with Autism Spectrum Disorders and other developmental disabilities.

AIR-B Research Project Summary

The AIR-B network consists of researchers at UCLA, University of Washington, University of Michigan, Kennedy Krieger Institute, Florida State University, and RAND. We have three research protocols in progress. All of these protocols are focused on underserved and underrepresented populations and issues in autism (core deficits of social communication in children with limited language, social skills and peer relationships of children in schools and children from diverse economic and ethnic/cultural backgrounds). Each protocol involves approximately 200 children.

- Protocol 1 focuses on a home based caregiver mediated intervention for preschool aged children to improve social communication outcomes of children.
- Protocol 2 is situated in schools for children who are fully included in general education classrooms. The goal is to compare two different peer interaction and social skill development interventions.
- Protocol 3 develops a novel web based delivery of a social skills intervention for children who have limited access to social skills interventions.
- Finally, initial efforts have already been leveraged in the funding of a fourth protocol that focuses on interventions for social skills and peer interactions of adolescent children with autism.

The AIR-B network has made significant progress towards their research protocols, guideline development, and dissemination activities. Research protocols have been codified, circulated and accepted by Network members. Pilot data were collected for both protocols, IRB approvals have been obtained or are pending. Data collection has begun on Protocol 2 at UCLA. Additional research protocols and supplements have been submitted for funding that involve the collaborations of the AIR-B network.

AIR-B Guideline and Tool Development

Goals of AIR-B are also to bridge research to practice by validating instruments for core deficits that can be easily implemented by practitioners and developing a set of guidelines for evidence-based interventions that can be utilized by health professionals and families. Guideline development is far along with completion of literature searches and near completion of data abstraction. The RAND Group has made substantial progress in initiating work on guideline development relating to psychosocial intervention for individuals with ASD. RAND has staffed its internal team who will be responsible for literature screening, collation, review, summary, and preparation for assessments by the Expert Panel. The external Expert Panel has been selected, with selections reviewed and approved by the AIR-B investigators. Two meetings of the Expert Panel have been held for review and feedback on the guideline project. Literature and data are currently being collected and weekly conference calls are held. Currently quantitative analyses are being performed with completion of the evidence report expected by year-end. Face-to-face guidelines development meetings are planned for early spring 2010.

Dissemination activities have been initiated and involve the development of a survey of professionals in the AIR-B group, the development of an AIR-B website with logo, and the design of web-based training manuals. Tool development will be carried out in the context of our research studies.

MCH Autism Intervention Research Program

This program supports research on evidence-based practices for interventions to improve the health and well-being of children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities. Projects funded in FY2009 include:

- ***“Assessing a Participant Directed Service System for Low Income Children with Autism”***

Marji Erickson Warfield of Brandeis University is evaluating a Medicaid supportive services waiver program in Massachusetts that uses a participant direction (PD) model to choose and manage services for young children with autism spectrum disorder (ASD) and their families. Families work with a support broker from one of seven local Autism Resource Centers to choose services, supports, and providers. A case manager from a state agency coordinates the clinical services, and a worker from a fiscal intermediary helps families with provider management and payment responsibilities.

- ***“Supporting the Well-being of Families of Young Children with Autism Spectrum Disorders”***

Emily Feinberg, ScD, of Boston University School of Medicine and Boston Medical Center, is trying to determine whether an evidenced-based empowerment strategy, Problem Solving Education (PSE), targeted to mothers of young children with autistic spectrum disorders (ASDs), promotes family well-being by decreasing the burden of maternal depressive symptoms and parenting stress and improving maternal social functioning.

- ***“Parent-Mediated vs. Center-Based Intervention for Toddlers with ASD: An RCT***
Led by Rebecca Landa, Ph.D., CCC-SLP, of the Kennedy Krieger Research Institute. At present, most Part C services for children at risk for ASD are provided in the home where a parent-mediated model is emphasized. Research is needed to evaluate whether parent-mediated intervention and center-based intervention provided by a clinician yield comparable outcomes for minority and underserved toddlers with ASD. The goal of the proposed research is to challenge existing intervention paradigms for young minority and underserved children with ASD and their families.

- ***“Family-Centered Transition Planning for Students with Autism Spectrum Disorders”***

This project is led by David Hagner, Ph.D. at the University of New Hampshire. Young adults with Autism Spectrum Disorders (ASD) frequently transition from high school to adult life lacking the skills and supports needed to participate as full members of their communities. The resulting social isolation and dependency on families or intensive disability support services has been identified as a serious social problem, compounded by a significant increase in incidence of ASD diagnosis in recent years. The Institute on Disability at the University of New Hampshire and the Center for Community Inclusion and Disability Studies at the University of Maine will demonstrate a Family-Centered Transition Planning model.

- ***“Telehealth Delivery of a Family-Focused Intervention to Reduce Anxiety in Youth with Autism Spectrum Disorders in Rural Colorado”.***
Susan Hepburn, PhD., of the University of Colorado Denver is directing this project aimed at the development and evaluation of interactive televideo technology to deliver a promising mental health intervention to families of children with ASD who are geographically removed from specialty medical centers.

MCH Autism Intervention Secondary Data Analysis Studies Program

This program supports research on evidence-based practices for interventions to improve the health and well-being of children and adolescents with autism spectrum disorders (ASD) and other developmental disabilities, utilizing exclusively the analysis of existing secondary data. Two projects were funded in FY2009 and are just getting underway.

- ***“Services and Outcomes for Transition Age Young Adults with Autism Spectrum Disorders: Secondary Analysis of the NLTS2 and RSA 911”.***

John Butterworth, Ph.D., Institute for Community Inclusion, University of Massachusetts Boston. The goal of this project is to support the design of effective transition services and supports for students with ASD by identifying personal and programmatic factors that are related to positive postsecondary outcomes and understanding the differences in services and supports used by young adults with ASD compared to other young adults with disabilities.

- ***“The Effectiveness of Special Education Services for Children with Autism: A National Longitudinal Study”.***

No nationally representative, longitudinal data are currently available on children and youth with Autism. However, recent data from the U.S. Department of Education’s Office of Special Education Programs include adequate numbers of autistic youth and represent an important new opportunity to learn about these children and how they fare in the educational system. These data include the Pre-Elementary Education Longitudinal Study (PEELS), the Special Education Elementary Longitudinal Study (SEELS), and the National Longitudinal Transition Study-2 (NLTS2). These studies represent the experiences, special services, and outcomes of children throughout their school years and beyond.

Combating Autism Act Initiative State Autism Implementation Grants



Overview

State Implementation Grants for Improving Services for Children and Youth with Autism Spectrum Disorder (ASD) and other Developmental Disabilities



Six Original Grantees (awarded in 2008)

- Illinois
- Wisconsin
- Alaska
- Washington
- Missouri
- Utah



Three New Grantees (awarded in 2009)

- Rhode Island
- New Mexico
- New York



Overview

- **Panelists**
 - Illinois and Wisconsin
 - Alaska and Washington
 - Missouri and Utah
- **Format**
 - Model/Collaborators
 - National Performance Measures
 - Successes and Challenges



Illinois & Wisconsin Sandy Tiahr



**Charting the Course
Tracking Progress**

CAAI Meeting 2009



Collaborators

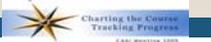
<p><u>Illinois</u> – The Autism Program of IL (TAP)</p> <ul style="list-style-type: none"> • 12 TAP Centers across Illinois <ul style="list-style-type: none"> ○ Universities ○ Agencies • Other Agencies & Programs <ul style="list-style-type: none"> ○ ARC of Illinois ○ DSCC ○ HFS ○ ICAAP 	<p><u>Wisconsin</u> – Title V</p> <ul style="list-style-type: none"> • Partnership with the University of Wisconsin’s Waisman Center • Five Regional Centers for CYSHCN • MCHB Partners <ul style="list-style-type: none"> ○ MCH LEND ○ Family to Family Health Information Centers
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National Performance Measure #1

Families will partner in decision making

<p style="text-align: center;">Illinois</p> <ul style="list-style-type: none"> • Illinois developed a curriculum for families to enhance the Family/Physician partnership of ARC Family to Family • Families assisted in creating a link to their Primary Care Physicians 	<p style="text-align: center;">Wisconsin</p> <ul style="list-style-type: none"> • Partners with ASD specific family organizations, Family Voices and Parent to Parent • Parents actively participate in all aspects of grant including a parent of a young child with ASD is the training and outreach coordinator for the grant
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National Performance Measure #2

CYSHCN will have access to medical home

Illinois	Wisconsin
<ul style="list-style-type: none"> • Early Autism and Referral training provided to Primary Care physicians • Medical Home information provided to physicians • 6 Primary Care practices will initiate a Medical Home with monthly Quality Improvement Team meetings 	<ul style="list-style-type: none"> • Training and Technical Assistance to Primary Care Providers to spread Medical Home quality improvements through: <ul style="list-style-type: none"> ○ Early developmental screening ○ ASQ-3 and MCHAT ○ Linking to community resources ○ Follow-up technical assistance



Charting the Course Tracking Progress
CAAI Meeting 2009

Successes

Illinois Wisconsin

<ul style="list-style-type: none"> • Increased linkage between system components – Families/Medical Community/ Professional Community • Families and the Medical community have increased awareness of available systems of care • The Medical and Professional Communities are rallying around Autism 	<ul style="list-style-type: none"> • The establishment of the Wisconsin Community of Practice on ASD and other Developmental Disabilities (CoP-ASD/DD); an approach to increasing collaboration across key partners. • Regional Resource Mapping is strengthening state resource database and regional partnerships
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Challenges

Illinois Wisconsin

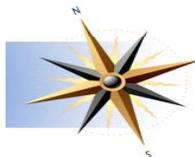
<ul style="list-style-type: none"> • Need to expand access to appropriate services, balanced by a focus on quality • This results in questions regarding the level of expertise required to provide diagnostics, treatment, and education • Questions are being posed in a system lacking appropriate ASD expertise 	<ul style="list-style-type: none"> • Some advocates question whether CAAI truly addresses the needs of “other developmental disabilities,” and Wisconsin looks for ways to assure that our work impacts the broader CYSHCN population including ASD
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Charting the Course Tracking Progress
CAAI Meeting 2009

Alaska & Washington

Kris Green



Charting the Course Tracking Progress

CAAI Meeting 2009

Collaborators

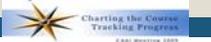
<p>Alaska – Title V (Div. of Public Health)</p> <ul style="list-style-type: none"> • Partners: <ul style="list-style-type: none"> ○ Governor’s Council on Disabilities & Ed. (Autism Ad Hoc Committee) ○ University of Alaska <ul style="list-style-type: none"> ▪ Center for Excellence in DD ○ State Agencies <ul style="list-style-type: none"> ▪ Infant Learning Program/Behavioral Health/Disabilities Services, etc. ○ Families ○ Tribal Health Organizations ○ Health Providers (including Children’s Hospital at Providence) ○ Child Care Providers ○ Multiple local organizations 	<p>Washington– Title V (Dept. of Health)</p> <ul style="list-style-type: none"> • Partners: <ul style="list-style-type: none"> ○ UW LEND Program ○ Autism Society of Washington ○ Three State Children’s Hospitals ○ UW Autism Center ○ Disability Council ○ Schools ○ Birth to Three ○ Military ○ Autism Coalitions ○ Multiple local organizations
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National Performance Measure #3

CYSHCN will have adequate insurance

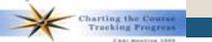
<p style="text-align: center;">Alaska</p> <ul style="list-style-type: none"> • House Bill 187 <ul style="list-style-type: none"> ○ Governor’s Council Initiative – supported by CAAI & committees • Public Resource Collaboration <ul style="list-style-type: none"> ○ Public Assistance/Medicaid 	<p style="text-align: center;">Washington</p> <ul style="list-style-type: none"> • Collaborate with parents & providers <ul style="list-style-type: none"> ○ Improve access to: <ul style="list-style-type: none"> ▪ Evidence-based medicine ▪ Systems of care ▪ Medical education & licensure standards
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National Performance Measure #4

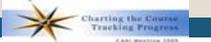
Children will be screened early and continuously

<p style="text-align: center;">Alaska</p> <ul style="list-style-type: none"> • Train multidisciplinary providers <ul style="list-style-type: none"> ○ Develop & deliver provider specific trainings ○ Streamline screening & referral process (rural focus) • EPSDT collaboration <ul style="list-style-type: none"> ○ Public Health Nursing ○ Headstart 	<p style="text-align: center;">Washington</p> <ul style="list-style-type: none"> • Subcommittee work: <ul style="list-style-type: none"> ○ Community asset mapping ○ Capacity building • CAAI, LEND & expert mentors provide TA
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Successes

<p style="text-align: center;">Alaska</p> <ul style="list-style-type: none"> • New and renewed connections with Tribal Health Organizations and other statewide health and autism resources • Rapid Workforce Development planning • Tailored trainings for health care workers (rural focus) 	<p style="text-align: center;">Washington</p> <ul style="list-style-type: none"> • LEND/CAAI Advisory Council partnership • Stakeholder investment is rich and diverse • Local communities excited to engage on many levels <ul style="list-style-type: none"> ○ Screening ○ Training ○ Capacity
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Challenges

Alaska	Washington
<ul style="list-style-type: none"> • Geographic and cultural differences <ul style="list-style-type: none"> ○ Rural/Bush communities are extremely isolated (no road system) with limited health resources ○ In-state travel costly and difficult • “Silo” agencies <ul style="list-style-type: none"> ○ Need increased knowledge of other provider roles/resources • Lack of service providers <ul style="list-style-type: none"> ○ Urban and Rural issue 	<ul style="list-style-type: none"> • Large interest and Council membership <ul style="list-style-type: none"> ○ Control of process and communication • New Staff Hiring Process <ul style="list-style-type: none"> ○ Timeliness/team building ○ Economic barriers (time, regulations, contracts, etc.) • Geographic (large state) <ul style="list-style-type: none"> ○ Travel costly and time consuming

Missouri & Utah Janet Farmer

Collaborators

<p>Missouri – University of Missouri</p> <ul style="list-style-type: none"> • Partners: <ul style="list-style-type: none"> ○ Department of Health/Title V ○ Department of Mental Health/Developmental Disabilities ○ UCEDD/UMKC/LEND ○ MO-FEAT, MO Family Voices ○ MO Centers for Autism & DDs 	<p>Utah – Title V</p> <ul style="list-style-type: none"> • Partners: <ul style="list-style-type: none"> ○ UT State Univ. Center for Persons with Disabilities ○ Univ. of UT Health Sciences Center, Dept of Pediatrics ○ UT Family Voices ○ UT Pediatric Partnership to Improve Healthcare Quality
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National Performance Measure #5

Community-based services will be organized

<p style="text-align: center;">Missouri</p> <ul style="list-style-type: none"> • ASD care coordination program expanded to 3 sites • Dissemination of MO ASD Navigation guide 	<p style="text-align: center;">Utah</p> <ul style="list-style-type: none"> • Enhanced evidence-based information available on Medical Home website: medicalhomeportal.org
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National Performance Measure #6

CYSHCN will receive the services necessary to transition

Missouri	Utah
<ul style="list-style-type: none"> • Autism Intervention Conference featured transition workshops • Statewide Youth Advisory Council and ASD Youth Coalition 	<ul style="list-style-type: none"> • Trained Family Navigators to support families • Family conference regarding Utah systems of care



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Successes

Missouri	Utah
<ul style="list-style-type: none"> • ASD training module online • Family Mentoring expansion • Missouri Autism Guidelines Initiative 	<ul style="list-style-type: none"> • Medical Home Learning Collaboratives: Completed for medical teams and scheduled for dental teams



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CAAI Meeting 2009

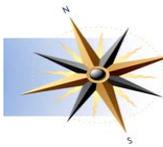
Challenges

Missouri	Utah
<ul style="list-style-type: none"> • Role of Title V program 	<ul style="list-style-type: none"> • Recruiting family physicians for Medical Home Learning Collaboratives



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Thank You



Charting the Course
Tracking Progress

CAAI Meeting 2009

ALASKA

Alaska's Rapid Response – Autism (2008 grantee)

Contacts: Kris Green (kristine.green@alaska.gov) and Jimael Lawson (jimael.lawson@alaska.gov)

Overview:

The State of Alaska collaborates with a variety of government, local, and tribal organizations to identify and recruit invested stakeholders to address the three primary goals of the Combating Autism Act Initiative (CAAI) state demonstration grant:

1. Improve rural services for early identification, screening and diagnosis of children with autism spectrum disorder (ASD) by developing rapid responder teams and streamlined referral process.
2. Connect ASD affected children ages 0-3 with Infant Learning Program (ILP) services and a medical home.
3. Align with established service improvement planning.

Building on the 2006 State Autism Plan from the Governor's Council on Disabilities and Special Education (GCDSE), stakeholders participated in discussions on bridging cultural gaps related to early identification and treatment of autism in rural Alaska. By successfully engaging in a multi-disciplinary team approach with stakeholders from ILP, public health nursing, schools, tribal health organizations, community health providers, and the Providence Neurodevelopmental Center, culturally relevant training, resources, and awareness tools were identified as we investigated the cultural implications of the CDC's "red flags." Such information could have far reaching implications in the field of autism research. The CAAI grant efforts align goals with the State Autism Plan which focuses on 1) infrastructure development; 2) universal screening; 3) diagnostic clinic expansion, 4) resources, referral and training with workforce training; and 5) time-limited intensive early intervention.

ILLINOIS

The Autism Program of Illinois (TAP) (2008 grantee)

Contact: Georgia Winson (gwinson@thehopeinstitute.us)

Sandy Tiaht, Julie Munoz-Najar, Dwight Robinson (IMPACC@thehopeinstitute.us)

Overview:

TAP Service Network provides a natural forum for the implementation of "A Statewide Collaborative to Improve Services for Children with Autism and Developmental Disabilities". The intensive linkage and technical assistance initiative outlined in "*IMPACC Collaborative: Improving Access to Community Care for Individuals with ASD and DD*" is consistent with the Healthy People 2010 initiative goal HP #16-22: Increase the proportion of children with special health care needs who have access to a medical home. IMPACC will provide community-based outreach to primary care physicians through training, resource sharing, and direct family to physician interactions all designed to increase the number and quality of medical homes serving children with ASD and DD. Although Division of Specialized Care for Children (DSCC) is reaching out to a variety of Children with Special Health Care Needs (CSHN) ASD is not specifically covered as an eligible diagnosis under DSCC. The project is building upon the TAP Service Network by extending the type of services currently provided by DSCC to children, with a range of special healthcare needs, to the ASD DD population. IMPACC will build service capacity and the stability and resiliency of the system of care through targeted interventions that link, train and support the application of medical home principles in the comprehensive care of individuals with ASD and DD.

MISSOURI

The Rapid Response Project: Implementing Missouri's ASD Roadmap (2008 grantee)

Contact: Janet Farmer, PhD ABPP farmerje@health.missouri.edu

Overview:

To improve access to comprehensive coordinated health care and related services for Missouri children and youth with autism spectrum disorders and other developmental disabilities.

- To improve access to comprehensive and coordinated care through the Medical Home
- To support successful adolescent transition to adulthood for youth with ASD
- To ensure the sustainability of access to comprehensive and coordinated care

These goals will be accomplished through collaborative activities supported by the Missouri Rapid Response team. The leaders of this team includes representatives from the Division of Developmental Disabilities in the Department of Mental Health, the Bureau of Special Health Care Needs in the Department of Health and Senior Services, University-affiliated developmental centers, primary and specialty care physicians and family advocates. The University-affiliated centers include the University of Missouri-Columbia Thompson Center for Autism & Neurodevelopmental Disabilities [funded agency]; University of Missouri-Kansas City Institute for Human Development and Children's Mercy Hospital; St. Louis University Knights of Columbus Child Development Center and Southeast Missouri University Center for Autism Diagnosis and Treatment. These partners will work together to enhance early identification and intervention, individual and family supports, health care quality improvements and systems changes that support children, youth and families.

UTAH

Utah ASD Systems Development Project (2008 grantee)

Contacts: Holly Williams (hollywilliams@utah.gov) and Rebecca Giles (rgiles@utah.gov)

Overview:

The purpose of the Utah Autism Spectrum Disorders (ASD) Systems Development Project (UT ASD) is to implement key components of "Utah's State Plan for Improving Outcomes for Children with ASD and Developmental Disabilities (DD)" to improve access to comprehensive, coordinated, community-based health care, and related services for children and youth with ASD and DD and their families. Over the three-year funding cycle, the Utah Department of Health (UDOH) Bureau of Children with Special Health Care Needs (BCSHCN) and key partners will implement projects to train pediatricians, family practice physicians, dentists, early childhood educators, and early intervention specialists. The project will also increase access to information and community resources for families and providers. Key partners, including BCSHCN (funded agency), Utah State University Center for Persons with Disabilities (USU CPD), University of Utah Health Science Center Department of Pediatrics (UHSU DP), Utah Family Voices, and Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ), will coordinate the project with community advocates, parents and providers for individuals with ASD.

WASHINGTON

Autism Awareness: Partnership for Change (2008 grantee)

Contacts: Maria Nardella, Project Director (maria.nardella@doh.wa.gov) and Carol Miller, Project Coordinator (carol.miller@doh.wa.gov)

Overview:

Overall purpose of this grant is to improve access to comprehensive, coordinated health care and related services for Washington children and youth with autism spectrum disorder (ASD) and other developmental disabilities.

Three main goals for the work activities:

- A. Engaging and empowering new stakeholders
 - a. Combating Autism Advisory Council
 - b. Community Empowerment Partnership for Autism Awareness
- B. Coordinating training for providers and families
 - a. Families
 - b. Providers
 - c. Quality Assurance
- C. Impacting existing benefit systems for children with ASD

WISCONSIN

Connections (2008 grantee)

Contacts: Sharon Fleischfresser MD, MPH Sharon.fleischfresser@wi.gov; Amy Whitehead, MPA, amy.whitehead@wi.gov

Overview:

The Children and Youth with Special Health Care Needs (CYSHCN) Program within the Department of Health Services aims to strengthen the state's infrastructure to improve services for children with ASD and other Developmental Disabilities (ASD/DD). The University of Wisconsin-Madison Waisman Center and the Regional Centers for CYSHCN are key collaborators. Below are the primary regional and statewide activities.

Regionally

- Regional Resource Mapping: The Regional Centers utilize a core team representing a diversity of stakeholders, to conduct regional resource mapping which identifies and catalogues ASD/DD regional assets and gaps.
- Regional Trainings: Two training strands target primary care providers and community providers and families to address early identification and ASD-specific content respectively.

Statewide

- Community of Practice (CoP): A statewide CoP on ASD/DD brings diverse partners together to learn about research of national significance on ASD; collaborate and strengthen connections; and work in Practice Groups around a shared interest.
- Outreach: CDC's Act Early outreach campaign is being implemented to increase awareness, evidence-based diagnosis and referrals to impact communities, parents and professionals.
- Electronic Repository: A website is established to provide a single place where information related to Wisconsin ASD resources can be accessed.

NEW MEXICO

New Mexico ASD Regional Resource Center (ASD-RRCs) (2009 grantee)

Contact: Pat Osbourn

Overview: The initial three-year proposal called for the establishment of five ASD Regional Resource Centers throughout the state of New Mexico. Current goals include:

- Establish four ASD Regional Resource Centers (ASD-RRCs) throughout the state of New Mexico
 - Establish the existing New Mexico Autism Taskforce as the Advisory Board for the ASD-RRCs
 - Establish linkages in Northern NM, Southern NM, Albuquerque Metro Area, and NM Military Bases
 - Locate telehealth connectivity within regions
 - Establish regional partners/stakeholder group
- Establish linkages to support a medical home in each region of New Mexico to increase access to ASD supports
 - Elicit stakeholder perspectives to supplement existing statewide needs assessment with current community-based needs
 - Develop regional priorities based upon needs assessment and conduct outreach activities based on regional priorities
- Create a plan for sustainability of the ASD-RRCs.
 - Identify and coordinate existing funding and non-fiscal resources
 - Develop and implement revised or new policies, procedures, interagency agreements, regulations or statutes
 - Develop comprehensive evaluation plans

NEW YORK

NYS Partners for Healthy Futures for Children and Youth with Autism Spectrum Disorders (2009 grantee)

Contact: Donna M. Noyes, Ph.D., PI (Associate Director for Clinical Policy) dmn02@health.state.ny.us, Jeffrey Simon, Manager, Training and Technical Assistance Unit, Co-PI

Overview: The New York State Department of Health (lead agency for IDEA Part C Early Intervention Program and Title V CYSHCN Program) and partners will build upon the State's Interagency Autism Platform to implement a multifaceted plan to:

- Increase the proportion providers that perform ASD screening for all children at 18 and 24 months
- Train health care and special ed. professionals on the use of best practice Applied Behavioral Analysis (ABA) and other behavioral interventions
- Implement a quality improvement review tool to monitor the quality of ABA provided statewide
- Implement a Web-based family support initiative for parents of children with ASD to help improve their knowledge, satisfaction, access to care, and the quality of their child's transition between various components of the system.

RHODE ISLAND

State Implementation Grant for Improving Services for Children and Youth with ASD and other DD (2009 grantee)

Contact Person: Deborah Garneau

Overview: Rhode Island will implement an integrated community system of services for children/youth with ASD and other developmental disabilities. The proposed project will build on existing initiatives providing the basis for the ASD statewide infrastructure. The anticipated benefits of the proposed project include:

- All CYSHCN (including ASD and other DD) and their families will benefit from stronger partnerships with physicians in areas of family-centered care and cultural competence.
- All CYSHCN and their families will benefit from comprehensive health care through a medical home.
- All CYSHCN and their families will have access to early and continuous screening through the medical home and community partners.
- HEALTH will continue to work with Rhode Island's health plans to redesign their existing benefits package for CYSHCN to support services in a medical home.
- HEALTH and its partners will continue to work on ensuring that community resources are accessible and integrated.
- HEALTH and its partners will assure that a coordinated transition from adolescent to adult health for CYSHCN will occur.

National Performance Measure:	Alaska	Illinois	Missouri
#1: <i>Families of CSHCN will partner in decision making at all levels, and will be satisfied with the services they receive.</i>	<ul style="list-style-type: none"> -Autism & Parent Svcs Mgr hired to ensure parent/family inclusion in state collaborative process -CSHCN Parent Advisory Board created 	<ul style="list-style-type: none"> -Training Curriculum to engage families w/ physicians -Family Advisors (statewide) 	<ul style="list-style-type: none"> -Training for families to participate fully in decision making -Model for Family-Professional Task Force developed -Surveys adapted to assess family satisfaction
#2: <i>All CSHCN will receive coordinated ongoing comprehensive care within a medical home.</i>	<ul style="list-style-type: none"> -Tribal Health Collaboration (train providers within existing medical home system) 	<ul style="list-style-type: none"> -Develop communication protocol for PCPs & diagnostic teams -6 Medical Homes initiated (incorporate quality improvement teams) 	<ul style="list-style-type: none"> -Care coordination model developed to promote communication among families, health care providers and community agencies
#3: <i>All families of CSHCN will have adequate private and/or public insurance to pay for the services they need.</i>	<ul style="list-style-type: none"> -Public resource collaboration (Medicaid) -Support HB187 for private insurance ASD coverage 	<ul style="list-style-type: none"> -CPT coding for relevant ASD services identified -Create billing/sliding fee scale for services 	<ul style="list-style-type: none"> -Care coordination model includes access to financial resources -Parent and professional training in the area that Annual Autism Intervention Conference -Medicaid Autism Waiver and state autism insurance legislation
#4: <i>All children will be screened early and continuously for special health care needs.</i>	<ul style="list-style-type: none"> -Train multidisciplinary providers/streamline screening & referral process (especially rural) -EPSDT collaboration for increased early screening 	<ul style="list-style-type: none"> -Peer mediated model physician training –Early Autism Detection and Referral (collaborative effort) -Train total 120 practices (47 complete as of 11/09) 	<ul style="list-style-type: none"> -Leadership provided for Missouri Autism Guidelines for Screening, Diagnosis, Assessment --Developmental screening collaboration -Online autism training modules
#5: <i>Community-based service systems will be organized so families can use them easily.</i>	<ul style="list-style-type: none"> -Expand provider involvement -Increase private/public service agency participation 	<ul style="list-style-type: none"> -Cultural competency training developed (offered to 12 statewide TAP centers) -Referral protocol developed between TAP, Arc of Illinois & ASI 	<ul style="list-style-type: none"> -Dissemination of ASD Navigation Guide -Rapid Response Learning Collaboratives to be developed at four sites
#6: <i>CSHCN will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.</i>	<ul style="list-style-type: none"> -Capacity building -Workforce development (increase availability to specialized behavioral support providers) -Collaborate with state Behavioral Health “Bring the Kids Home” initiative (focus on transition age) 	<ul style="list-style-type: none"> -National Experts Conference participation -Hosted Autism Speaks Advancing Futures for Adults with Autism -Collaborate to create adult prototype Resource Room & replication manual 	<ul style="list-style-type: none"> -Youth Advisory Council -ASD Youth Coalition -Care coordination planning for youth

National Performance Measure:	Utah	Washington	Wisconsin
#1: <i>Families of CSHCN will partner in decision making at all levels, and will be satisfied with the services they receive.</i>	<ul style="list-style-type: none"> -Train Family Navigators -Conference regarding Utah systems of care -Adapted "Autism ABCs" -Enhanced evidence-based info available on Medical Home website -"Learning collaborative" with Utah Family Voices 	<ul style="list-style-type: none"> -Family voice & parent participation at council & subcommittee meetings -Family Involvement Subcommittee target issues -11,000 copies of Autism Guidebook for WA State distributed 	<ul style="list-style-type: none"> -Family Voices/family partnership integral to Steering Team & information dissemination (Family-to-Family Health Information Network). -Parents actively participate in each Community of Practice (CoP) meeting
#2: <i>All CSHCN will receive coordinated ongoing comprehensive care within a medical home.</i>	<ul style="list-style-type: none"> -"Learning collaborative" of 8 pediatric practices using medical home model -Needs assessment for "Dental Home" model development 	<ul style="list-style-type: none"> -Subcommittees work on community asset mapping & capacity building -Medical Home teams work with champion community peers -CAAI, LEND & expert mentors provide TA 	<ul style="list-style-type: none"> -Primary Care Provider training designed to strengthen & promote Medical Home quality improvements
#3: <i>All families of CSHCN will have adequate private and/or public insurance to pay for the services they need.</i>	<ul style="list-style-type: none"> -Train Family Navigators to support newly diagnosed ASD children/families 	<ul style="list-style-type: none"> -Collaborate with parents & providers to improve access to evidence-based medicine, systems of care, and medical education/licensure standards 	<ul style="list-style-type: none"> -Support MCH LEND MPH trainee to develop training model for new ASD state insurance mandate
#4: <i>All children will be screened early and continuously for special health care needs.</i>	<ul style="list-style-type: none"> -"Learning collaborative" of 8 pediatric practices using medical home model -"Child Find" campaign pilot using CDC materials 	<ul style="list-style-type: none"> -Subcommittees work on community asset mapping & capacity building -CAAI, LEND & expert mentors provide TA 	<ul style="list-style-type: none"> -Primary Care Provider trainings focus on implementation strategies for early and continuous developmental screening
#5: <i>Community-based service systems will be organized so families can use them easily.</i>	<ul style="list-style-type: none"> -Enhanced evidence-based info available on Medical Home website 	<ul style="list-style-type: none"> -Subcommittees work on community asset mapping & capacity building -CAAI, LEND & expert mentors provide TA 	<ul style="list-style-type: none"> -Infrastructure development using National Medical Home Autism Initiative, ASD Roadmap & WI specific plan to improve services
#6: <i>CSHCN will receive the services necessary to make transitions to all aspects of adult life, including adult health care, work, and independence.</i>	<ul style="list-style-type: none"> -Train Family Navigators to support newly diagnosed ASD children/families -Conference regarding Utah systems of care 	<ul style="list-style-type: none"> -Collaborate with parents & providers to improve access to evidence-based medicine, systems of care, and medical education/licensure standards 	<ul style="list-style-type: none"> -Established Statewide Community of Practice on ASD/DD. -Practice group on Transition to share info, regular meetings to address shared areas of interest and work.



CAAI Annual Meeting: Opportunities for Systems Change

Paula C. Durbin-Westby
Autistic Self Advocacy Network



**Academic Autistic Spectrum Partnership
In Research and Education**
www.aaspire.org



AUCD Partnering Project

- CBPR collaboration between:
- Rural Institute in Montana
- Regional Resource Institute in Portland, OR
- Self Advocates Becoming Empowered (Montana and Oregon chapters)
- Autistic Self Advocacy Network (Portland chapter)
- ASAN was solicited for participation in order to facilitate involvement by the Autistic community in the project.



Systems Change: Language Use and Metaphors for Autism

- “The purpose of the legislation is to amend the Public Health Service Act to combat autism through increased screening, intervention and education.”



Early Identification

- Diagnosis
- Assessment



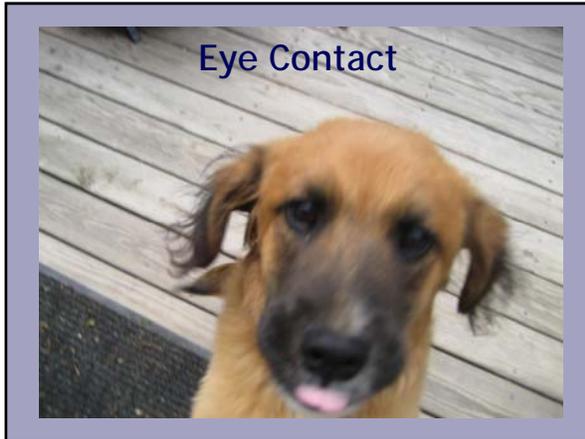
Intervention/Alternatives

- What does “Act Early” mean?:
- Assess strengths and difficulties
- Teach to strengths
- Address difficulties in a manner that is positive and respectful
- No stereotypes about what a person can or can’t achieve.



Intervention/Alternatives

- What does “Act early” NOT mean?
- “Let’s try something, anything!”
- Input from autistic adults invaluable:
- Find out from us what works, what does not
- “New discoveries” have been talked about for years on autistic forums online: *eye contact*



pdw15
ASAN
The Autistic Self-Advocacy Network

Intervention/Alternatives

- “Normalization” 
- vs.
- Individualized program

ASAN
The Autistic Self-Advocacy Network

Intervention/Alternatives

- Recovery research:
- Co-occurring conditions still present
- Inhibition of “core features” vs. “losing” core features?
- Learning skills and developing, rather than “recovery.”

ASAN
The Autistic Self-Advocacy Network

Interventions/Alternatives

- Behavior-specific:
- positive behavioral supports
- ABA
- various other programs and techniques



Stakeholders: Adults on the Spectrum

- Respectful language/concepts
- Respectful educational and other initiatives
- Move away from institutionalization
- Person-centered planning



Stakeholders: Adults on the Spectrum

- Expanding focus on whole individual
- Lifespan approach
- Meaningful gains over lifetime
- Transition periods



Expanding Focus on Whole Individual: Balanced view of Autism

- Strengths and weaknesses in each individual
- Research into strengths can translate to meaningful outcomes
- Research into differences can look at positive aspects of differences



Quality of Life Issues

- Domains measured by World Health Organization Quality of Life Instrument:
 - Social Relationships & Social Support
 - Physical Health
 - Mental Health/Psychological Health
 - Independence: Mobility, Activities of Daily Living, Communication & Work Capacity
 - Transportation Access
 - Vocation
 - Recreation & Leisure



Stakeholders: Children on the Spectrum

- Have the right to self-actualization
- Individualized programs that are more “supports” than “interventions.”
- Consult with autistic adults on both general principles and individual cases



Stakeholders: Parents

- Easily accessible *non-biased* information about autism.
- Website portal for information access
- Counseling, follow-up after diagnosis
- Service delivery infrastructure transparent
Parents should not have to wait years to find out details about Medicaid waivers, EDCD, etc.



Stakeholders: Parents on the Spectrum

- Are often more tolerant of children’s differences
- Are an invaluable source of information and expertise on autism
- Autistic adults involved in development of materials for parents (both for non-autistic and autistic parents)
- Are less tolerant of coercive “treatments”
- May need help navigating service systems
- May be subject to stereotypes about their parenting: Don’t assume poor parenting



Stakeholders: Professionals

- CAAI Programs
- Federal level
- State agencies
- Programs: Head Start, Early Start, Healthy Start



Stakeholders: Autistic Professionals

- SLPs
- DBPs
- OTs
- Special education teachers

- Agency officials
- Programs: Head Start, Early Start, Healthy Start



Delivery systems (examples)

- OCALI-Autism Internet Modules
- Virginia-Easy Access, JLARC recommendations, VA Board for People w/ Disabilities
- Include inter-state efforts
- Accessible to people with disabilities, including autism, hearing and visual disabilities



Systems Change

- Inclusion of autistic people in meaningful ways
- Culturally competent approach
- What is the “culture”? Autistic individuals, families, communities, carers, shared interests or patterns of characteristics/behaviors:
- Autreat example, ASAN example



LEND Directors CAAI Survey Results 2009



1

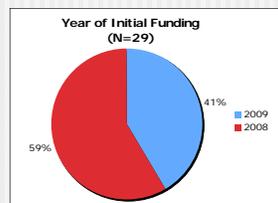
Survey Questions

- Survey addressed three main questions relating to:
 - Challenges in implementing ASD services and training
 - Successful Aspects of Programs due to ASD Expansion Funding
 - Types of Collaboration with other LEND Programs or ASD Agencies

2

Respondents

- A total of 29 LEND directors responded to the survey. Of these, 17 received funding in 2008, and 12 received funding in 2009.



3

Question 1: Challenges of Implementing ASD Services and Training

- Integrating Curriculum
- Trainee Recruitment
- Implementing Curriculum
- Lack of Funding or Staff
- Late Notification of Funding
- None

4

Integrating Curriculum

- Expanding an already full curriculum to focus on ASD
 - “The biggest challenge to date has been how to integrate the ASD content into our already existing curriculum. **The current curriculum is already quite intense...**”
- Need to revise requirements in curriculum due to new CAAI goals

5

Trainee Recruitment

- Difficulty recruiting trainees due to late notification of award
 - “Recruiting **trainees that can dedicate their time to a robust LEND core curriculum** and ALSO expand to an additional ASD specialization”
- Difficulty recruiting students from racial and ethnic minority groups

6

Implementing Curriculum

- Limited time to implement goals
- Interdisciplinary group
 - “Being a broadly interdisciplinary group of trainees, implementing training that allows trainees to screen, diagnose and/or treat children who carry the ASD diagnosis is a bit **limited to those disciplines where that is appropriate...**”
- Involving trainees in screening and diagnosing ASD

7

Lack of Funding or Staff

- Cuts to state human service organizations
 - “Finding time to do everything with limited funds is a real stress. The **economic recession** has been a definite factor that has limited the availability of other funds...”
- Economic Recession
- Lack of capacity in current staff

8

Late Notification of Funding

- Integrating ASD programs with trainees who had already been recruited
- Allocation of staff time
 - “The faculty had also **already allocated their time for the fall** and the ASD training needed to be ‘fit in’”
- Notification came after potential trainees had already made commitments

9

Question 1: Responses to Challenges

- Revising Curriculum
- Seeking out Partnerships or Collaborations



10

Revising Curriculum

- Modifying existing curriculum
- Presenting content in different ways (e.g. online modules),
- Adding new types of training opportunities
- Remaining flexible with components of provided trainings
- Expanding training beyond the usual end date.

11

Seeking out Partnerships or Collaborations

- Other departments within university
- Other universities
- Community Agencies
- State Programs
- Sister Agencies
- Other CAAI programs



12

Question 2: Successful Aspects of Programs Permitted by ASD Expansion Funding

- Expand Curriculum or Training
- Establish New Programs
- Bring on More Trainees
- Bring on More Staff
- Product Development

13

Expand Curriculum or Training

- Providing more training content and more specialized content regarding ASD screening, diagnosis, and treatment.
- Expansion of training to more students, faculty, and community members.
- Online training content
- New core curriculum courses
- Advanced track for trainees interested in ASD

14

Establish New Programs

- New program within an existing preschool classroom
- Pilot project with M-CHAT screening
- State-wide educational initiatives
- Creation of screening and services clinics or centers

15

More Trainees

- Inclusion of additional family trainees
- Additional professional trainees
- Doctoral and post-doctoral trainees
 - “We were able to **fund two additional fellows** (doctoral students in early intervention) with the expansion funding...”



16

More Staff



- Staff who are trained in a train-the-trainer for ASD assessment and diagnostic tools
- Staff in a family mentorship program for families of children with autism
 - “The trainees spend time with the family doing family activities or going to appointments or school meetings...”

17

Product Development

- E.g. “We are working with an educational media company to **create on-line continuing education modules** for broad dissemination.”



18

Question 3: Collaboration Activities with other LEND Programs or ASD Agencies

- Workshops, Trainings, or Summits
- Training Development
- Technical Assistance & Consultation
- Program Development



19

Workshops, Trainings, or Summits

- Collaborating with other programs or agencies to develop workshops, trainings, or summits
- Putting on conferences
- Attending meetings with other programs
- Putting on consortiums

20

Training Development

- Developing new trainings for consumers outside of LEND, including:
 - Community members
 - Parents
 - State agencies
 - Physicians
 - Early Intervention Professionals
 - Other healthcare providers

21

Technical Assistance & Consultation

- Other LEND programs
- State Agencies
 - “LEND faculty are **providing technical assistance to the state** for the development of a severe behavior waiver.”
- School systems

22

Program Development

- Partnering with local government to create a community service alternative to the local hospital
- Collaboration with a local university to create a new educational program.

23

Question 3: Types of Collaboration with other LEND Programs or ASD Agencies

- Other LEND programs
- Local Community Collaborations
- Other Title V agencies
- State-level Collaborations
- Other Health-Related Programs
- Other National Networks

24

Conclusion

- CAAI funding has allowed programs to:
 - Put on additional workshops, trainings, & summits related to ASD
 - Provide additional technical assistance & consultation to communities
 - Expand curriculum and training
 - Establish new programs & clinics
 - Include additional trainees, faculty & staff
 - Develop new products

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Thank You

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The Family Navigator Clinic

University of Southern California
LEND Program

Sonia Konialian Aller, PhD, CCC

Fran Goldfarb, MA, CHES

Marian Williams, PhD

Marion Taylor Baer, PhD, RD

CAAI Meeting

December 8, 2009

The Problem/Rationale

A) Although under IDEA parents are considered full members of the child's IEP team, not all parents are comfortable in that role .

- They don't understand how their child is being assessed;
- They don't understand what the results mean in terms of strengths and weaknesses;
- They don't understand how the results are being used by the professionals to develop IEP goals.

The Problem/Rationale

B) Parents can obtain generic information through workshops, books, family resource centers, etc.

However...

- The information is not specific to their own child.

The Problem/Rationale

C) Parents can seek the services of a professional advocate or attorney when they cannot get satisfactory resolution to their concerns on their own.

However,

- The intended outcome is to resolve a specific issue, at a particular time, not to **increase the parent's effectiveness in advocating** when future issues arise.

The Problem/Rationale

D) Parents often demand more services when children don't make progress in their IEP goals, or when they feel their child's needs are not being adequately addressed.

However,

- Their demands may be arbitrary and may not be related to needs, or result in desired outcomes; or,
- They may be seeing their child's strengths and needs differently than the professionals; or,
- They may have valid concerns, but are unable to substantiate them.

The Problem/Rationale

E) Children w/disabilities receive evaluations and services in multiple domains and disciplines, requiring analysis and integration for a comprehensive perspective.

However:

- Most professionals/service providers are unidisciplinary in their knowledge base, and would have difficulty integrating multidisciplinary evaluations to help parents' advocacy efforts through the IEP process.

Target Population

➤ Families of children with ASD who have a child either:

- 1) transitioning to school from Part C, or
- 2) already receiving special education services but not meeting IEP goals

or who:

- 3) are requesting representation at the IEP but need intensive education (coaching) rather than advocacy training

Goal of the Clinic

- To increase the ability of parents of children with autism to competently participate in their child's educational planning through the IEP process. Parents are "coached" in:
 - the importance of their role and right to participate as a full member of the team.
 - the scope of special education, the concept of demonstrated need and its use in developing educational goals.
 - understanding their child's needs and how to facilitate a discussion around meeting them.

Training Goal

- Develop, in an interdisciplinary setting, trainees' parent-coaching skills:
 - To understand and interpret multidisciplinary assessments of children with autism;
 - To increase the parents' ability to competently participate in their child's IEP process.

Training Objectives

- Using adult learning principles, trainees will increase parents' effectiveness as equal members of the child's IEP team by training (coaching) them to:
 - Generate a profile of strengths and challenges of their child using current assessments, relate these to the current IEP and identify discrepancies.
 - Assess current school placement /level of supports and change /develop IEP goals.
 - Suggest interventions/supports for achieving goals.
 - Develop continuous monitoring strategies.



Jeffrey's Story

- **Mother's main concern:** Post-high school situation
 - Jeffrey, a teenager with Aspergers, is failing in high school, not meeting IEP goals, not attending school regularly
- **NC assessment:** intermediate issues not recognized:
 - Possible MH reasons for poor school attendance
 - Teachers unaware of IEP, focusing on poor parenting
- **NC Coaching activities** to support mother in:
 - Understanding intermediary steps
 - School attendance goal in IEP? Transportation? Psychotherapy?
 - Refocusing the school on the assessments supporting need for special education
 - Accessing adult supports soon to be available (SSI, etc.)
 - Accessing informational resources in Spanish, other supports for mother

Trainee Comments (current year)

- Impartial review
- Listening
 - Validating parents need to be assertive
- Positive spin on a negative experience
 - Parent support groups = feel good approach
 - Lawyer (P&A) = litigious approach
 - Navigator = teaching parents in an applied way
- “We are teaching parents how to fish instead of giving them a fish”

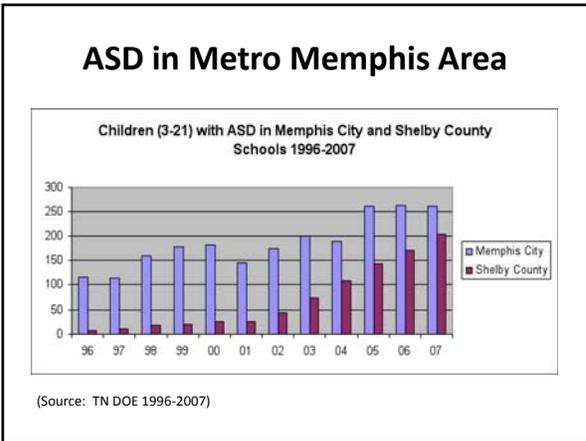
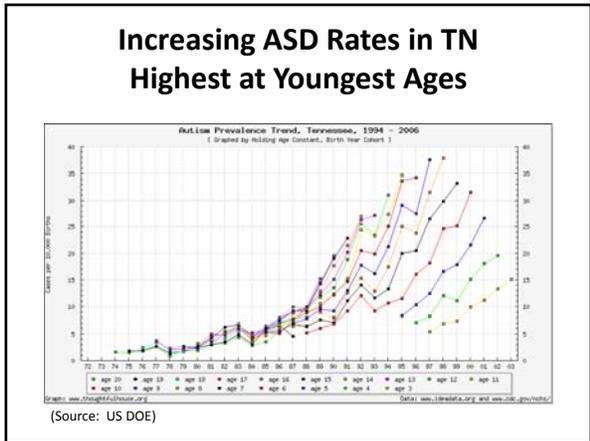
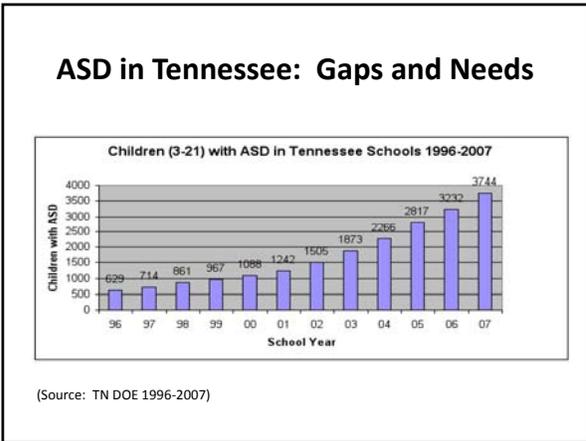
Ripples in Los Angeles (from training to service)

- **Southwest SELPA:** a LEND collaborator
 - “teacher-trainer” selected as a USC LEND fellow and member of the autism fellow team – beginning in 2008 - 2009
 - adapting the “Navigator Clinic” model this year with consultation from the USC team in the 12 districts
- **Lanterman Regional Center**
 - discussions under way for the USC UCEDD to provide a contractual service for their clients using the Navigator model

BCDD THE UNIVERSITY OF TENNESSEE HEALTH SCIENCE CENTER
BOLING CENTER FOR DEVELOPMENTAL DISABILITIES

ASD Community of Practice Model

Bruce L. Keisling, Ph.D.
 Associate Director
 Boling Center for Developmental Disabilities
 University of Tennessee Health Science Center

Need for Earlier Detection and Diagnosis

- For the 2007-2008 school year, TN Early Intervention System (TEIS) estimated 132 children under three years of age were enrolled in TEIS and diagnosed or suspected of having ASD (TEIS, 2008)
- This contrasts with a reported 481 children ages three to five with ASD enrolled in Tennessee schools during the 2006 school year (TN DOE 1996-2007).
- Efforts by trained professionals to improve early detection of ASD using valid tools are clearly indicated.

ASD Community of Practice

- Collaboration among TNAAP, Vanderbilt University Kennedy Center (VUKC), LeBonheur Children's Medical Center, TN Early Intervention System and TennCare, and with participation of medium-term and long-term LEND trainees
- Identify, train and support through the Community of Practice model (Kind, Benjamin et al. 2007) west Tennessee medical home pediatricians to detect, diagnose and care for children with ASD

Community of Practice: Local Members

- BCDD: Two developmental pediatricians, clinical psychologist and LEND family faculty coordinator
- One pediatrician, large urban practice
- One pediatrician, small suburban practice
- One bilingual pediatrician, small practice caring for Spanish-speaking families
- One pediatrician, supervisor of university-based (resident) continuity clinic

Community of Practice: Training

- Provide training in family-centered, culturally competent assessment and care of children with ASD to include the administration and interpretation of the *Screening Tool for Autism in Two-Year-Olds (STAT)* (Stone, Coonrod et al. 2000; Stone, Coonrod et al. 2004).
- Replicate the VKC training model (Warren, Stone, & Humberd 2009) for use of STAT in diagnosis of ASD in community pediatric practices

Community of Practice: Follow Through

- Model uses adult-learning strategies and includes: periodic group meetings and discussions; regular consultation through email, phone and password-protected intranet site; journal club; ongoing technical assistance
- Evaluate the effectiveness of the training, fidelity to the model; provide confirmatory, interdisciplinary evaluations for some cases



INSIGHT POLICY RESEARCH, INC.

Combating Autism Act Initiative Evaluation

MCHB GRANTEE MEETING
December 7-8, 2009

1



Presentation Overview

- Evaluation goals
- Evaluation schedule
- Data collection
- Reports
- Contact information

2



Our Goals

1. To gather the information that is needed to demonstrate the results of Federal investments in these grant programs (outputs and short term outcomes).

3



Our Goals

2. To identify collaborative activities across grantees that contribute to the accomplishment of MCHB's overall mission (i.e., whole is greater than the sum of its parts).

4



Our Goals

3. To provide Congress with data that tell a compelling story about what grantees have started to accomplish with Combating Autism Act funds.

5



Evaluation Schedule

- Phase I: Planning and Evaluation Design (Complete as of fall 2009)
- Phase II: Data Collection (June 2009-March 2011)
- Phase III: Data Analysis and Reporting (April 2011-September 2011)

6



Phase II: Data Collection

Existing Data Collection Tools:

- Grant applications
- Continuation applications
- DGIS

Insight will obtain these materials directly from MCHB

7



Phase II: Data Collection

Completed Activities:

- Reviewed grant applications for cohort 1 (FY08) and cohort 2 (FY09) grantees
- Reviewed year 1 continuation applications
- For LEND and DBP: Collected pilot data through NIRS new module

8


Phase II: Data Collection
New Data Collection Tools

LEND/DBP

- New NIRS module
- Semi-structured interviews

Research Programs (Networks and R40s)

- Questionnaire
- Semi-structured interviews

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Phase II: Data Collection
New Data Collection Tools (cont'd)

State Implementation Grantees

- Network Questionnaire
- Semi-structured interviews

TA Resource Centers (AUCD & AMCHP)

- Semi-Structured interviews

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Phase II: Data Collection
December 2009

- Semi Structured Interviews and discussions (Research Program, State grantees, DBP and LEND)
- Network Questionnaire (State grantees only)
- Research Network Questionnaire (Research Networks only)

11


Phase II: Data Collection
2010 Data Collection

- DGIS measures: Winter
- Continuation applications: Spring/Summer 2010
- NIRS (LEND and DBP only): July
- Begin final semi-structured interviews in December 2010 (LEND)

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Phase II: Data Collection

2011 Data Collection

- Final semi-structured interviews
 - DBP (ending in March 2011)
 - State Implementation grantees (ending in March 2011)
 - Research Programs (Networks and R40s)(ending in March 2011)
- NIRS (LEND and DBP only)
 - January 2011
- Interviews with TA Resource Centers (AUCD and AMCHP)
 - March 2011

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Phase III: Data Analysis and Reports

- MCHB Reports
 - An evaluation report will be developed for each grant program, summarizing the grantees' activities and progress towards meeting the goals of the Combating Autism Act Initiative
- Report to Congress
 - Insight will prepare MCHB's contribution to the Interagency Report to Congress

14



Building a Successful Evaluation Together...

- **Build trust and collaboration**
 - We respect that you are busy and will do everything we can to reduce your burden.
- **Learn more about each other**
 - We will seek your input all along the way—you are the experts.
 - There are some things only you can tell us.
- **Plan for reports with impact**
 - Your work matters.

15



Questions?

LEND:
 Claire Wilson
cwilson@insightpolicyresearch.com

DBP:
 Bryan Johnson
bjohnson@insightpolicyresearch.com

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Questions?

Research Programs (Networks & R40s)
Anne Peterson
apeterson@insightpolicyresearch.com

State Implementation grantees
Carol Irvin
Cirvin@mathematica-mpr.com

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We thank you for your cooperation!

Insight Policy Research
Mathematica Policy Research

18

Autism Treatment Acceleration Act of 2009

AUCD Detailed Summary

On April 2, Sens. Durbin (D-IL), Casey (D-PA), and Menendez (D-NJ) introduced the Autism Treatment Acceleration Act (S. 819) which was referred to the Senate Health, Education, Labor and Pensions Committee. On May 15, 2009 Reps. Doyle (D-PA) and Smith (R-NJ) introduced a companion bill in the House of Representatives (H.R. 2413).

The bill defines “autism spectrum disorder” as a developmental disability that causes substantial impairments in the areas of social interaction, emotional regulation, communication, and the integration of higher-order cognitive processes and which may be characterized by the presence of unusual behaviors and interests. Such term includes autistic disorder, pervasive developmental disorder (not otherwise specified), Asperger syndrome, Retts disorder, childhood disintegrative disorder, and other related developmental disorders.

Autism Care Centers Demonstration Project

Section 5 establishes a demonstration project for the implementation of an “Autism Care Center Program” to authorize HRSA to provide three year grants to a State or a public or private nonprofit entity to improve the effectiveness and efficiency in providing comprehensive care to individuals diagnosed with autism spectrum disorders (ASD) and their families. Autism Care Center is defined as a center that is directed by a primary care coordinator who is an expert in autism spectrum disorder treatment and practice and provides an array of medical, psychological, behavioral, educational, and family services to individuals with autism and their families.

Besides providing comprehensive care, other goals of the demonstration include:

- access to appropriate health care services, especially wellness and prevention care, at times convenient for patients;
- patient satisfaction;
- communication among autism spectrum disorder health care providers, behaviorists, educators, specialists, hospitals, and other autism spectrum disorder care providers;
- school placement and attendance;
- successful transition to postsecondary education, vocational or job training and placement, and comprehensive adult services for individuals with autism spectrum disorders, focusing in particular upon the transitional period for individuals between the ages of 18 and 25;
- the quality of health care services, taking into account nationally-developed standards and measures;
- development, review, and promulgation of common clinical standards and guide lines for medical care to individuals with autism spectrum disorders;
- development of clinical research projects to support clinical findings in a search for recommended practices; and

- improve the quality of life of individuals with autism spectrum disorders, including communication abilities, social skills, community integration, and employment and other related services; and
- decrease inappropriate emergency room utilization, which can be accomplished through initiatives such as expanded hours of care;
- decrease avoidable hospitalizations;
- decrease duplication of health care services;
- decrease the inconvenience of multiple provider locations;
- decrease health disparities and inequalities that individuals with autism spectrum disorders face; and
- decrease preventable and inappropriate involvement with the juvenile and criminal justice systems.

To be eligible for the grant, the State or non-profit entity agree to establish and implement an autism care center that:

- enables targeted beneficiaries to designate a personal primary care coordinator in such center to be their source of first contact and to recommend comprehensive and coordinated care for the whole of the individual;
- provides for the establishment of a coordination of care committee that is composed of clinicians and practitioners trained in and working in autism spectrum disorder intervention;
- establishes a network of physicians, psychologists, family therapists, behavioral specialists, social workers, educators, and health centers that have volunteered to participate as consultants to patient-centered autism care centers to provide high-quality care, focusing on autism spectrum disorder care, at the appropriate times and places and in a cost-effective manner;
- works in cooperation with hospitals,
- local public health departments, and the network of patient-centered autism care centers, to coordinate and provide health care;
- utilizes health information technology to facilitate the provision and coordination of health care by network participants; and
- collaborates with other entities to further the goals of the program, particularly by collaborating with entities that provide transitional adult services to individuals between the ages of 18 and 25 with autism spectrum disorder, to ensure successful transition of such individuals to adulthood

Planning and Demonstration Grant for Services for Adults

Sec. 6 of ATAA allows the Secretary to establish a one-time, single-year planning grant program for eligible entities; and a multiyear service provision demonstration grant program for selected eligible entities.

A State or non-profit receiving these grants are to carry out programs that focus on critical aspects of adult life, such as:

- postsecondary education, vocational training, self-advocacy skills, and employment;

- residential services and supports, housing, and transportation;
- nutrition, health and wellness, recreational and social activities; and
- personal safety and the needs of individuals with autism spectrum disorders who become involved with the criminal justice system.

The planning grants must be carried out in consultation with the State Developmental Disabilities Council and other organizations representing individuals with ASD and families.

The multi-year implementation grants will be awarded to eligible States that received a planning grant. The application for implementation grants must provide the following:

- the services that the eligible entity proposes to provide and the expected outcomes for adults with autism spectrum disorders who receive such services;
- the number of adults and families who will be served by such grant, including an estimate of the adults and families in under-served areas;
- the ways in which services will be coordinated among both public and nonprofit providers of services for adults with disabilities, including community-based services;
- the process through which the eligible entity will distribute funds to a range of community-based or nonprofit providers of services, including local governments, and such entity's capacity to provide such services;
- the process through which the eligible entity will monitor and evaluate the outcome of activities funded through the grant;
- the plans of the eligible entity to coordinate and streamline transitions from youth to adult services;
- the process by which the eligible entity will ensure compliance with the integration requirement provided under section 302 of the Americans With Disabilities Act of 1990 (4210 U.S.C. 12182); and
- a description of how such services may be sustained following the grant period.

National Registry for Autism Spectrum Disorders

Sec. 7 establishes a voluntary population-based registry of cases of ASD to facilitate the collection, analysis, and dissemination of data related to ASD. Activities of the Registry may include:

- implement a surveillance and monitoring system that is based on thorough and complete medical diagnosis data, clinical history, and medical findings;
- collect standardized information concerning the environmental, medical, social, and genetic circumstances that may correlate with diagnosis of autism spectrum disorders;
- promote the use of standardized autism spectrum disorder investigation and reporting tools of the Centers for Disease Control and Prevention, as well as standardized autism spectrum disorder protocols;
- establish a standardized classification system for defining subcategories of autism spectrum disorders for surveillance research activities; and
- support multidisciplinary reviews of autism spectrum disorders.

Multimedia Campaign

Sec. 8 authorizes the Secretary of HHS to award grants to public and nonprofit private entities to carry out multimedia campaigns to increase public education and awareness and reduce stigma concerning healthy developmental milestones and challenges that individuals with ASD face throughout the lifespan.

Interdepartmental Autism Coordinating Committee

Sec. 9 establishes an Interdepartmental Autism Coordinating Committee to coordinate all Federal efforts concerning ASD. Membership of the Committee shall be composed of the Director of NIH and other appropriate institutes; heads of other agencies within the Department of Health and Human Services; and representatives of the Dept. of Education, Defense, and other federal agencies that provide services to or have programs that impact individuals with ASD. Not less than 2/5 of the committee shall include non-public members appointed by the Secretary, of which at least one is an individual with ASD; one shall be a parent or guardian; one shall be a representative of a non-governmental organization; and one shall be a representative of a leading research, advocacy, or service organization. Members serve four year terms that may be renewed. Subcommittees on research, services and other topics may be established and may include individuals not on the Committee.

National Network for Autism Spectrum Disorders Research and Services

Sec. 10 authorizes the Secretary to establish a National Network for Autism Spectrum Disorders Research and Services composed of Federal, regional, State and local level entities to provide resources for and facilitate communication between, autism spectrum disorder researchers and service providers for individuals with autism spectrum disorders and their families.

The purposes of the National Network are to build upon the infrastructure relating to autism spectrum disorders that exists on the date of enactment of this Act; strengthen linkages between autism spectrum disorders research and service initiatives at the Federal, regional, State, and local levels; facilitate the translation of research on autism spectrum disorders into services and treatments to improve the quality of life for individuals with autism and their families; and ensure the rapid dissemination of evidence-based or promising autism spectrum disorder practices through a new National Data Repository for ASD Research and Services established under the Act.

A Committee of Regional Leaders shall be established to monitor, report, analyze, and disseminate information in the Data Repository and to facilitate communication between various members of the National Network. The Committee shall ensure regional participation through the appointment of regional leaders such as university- and community-based partnerships.

The Regional leaders will appoint State directors to coordinate the activities of the National Network at the State and community levels.

State Directors will establish State and community sub-networks to engage in frontline activities and provide direct services, including diagnostics, treatments, resource and referral, and support programs.

A contract will be made to a public or private nonprofit entity to establish a **National Data Repository** to collect, store, and disseminate information regarding research, data, findings, models of treatment, training modules, and technical assistance materials related to autism spectrum disorders in order to facilitate the development and rapid dissemination of research into best practices that improve care.

The Administrator of the Repository must collect information from ASD research and service agencies and organizations including: Centers of Excellence in Autism Spectrum Disorder Epidemiology; autism care centers; recipients of the adult services planning and implementation grants; UCEDDs or other recipients of training supplements; and the Regional, State and subnetworks.

National Training Initiatives on ASD

Sec. 11 of ATAA authorizes multiyear national training initiative supplemental grants to public or private nonprofit entities, including University Centers for Excellence in Developmental Disabilities and other service, training, and academic entities. The purpose is to provide training and technical assistance and to disseminate information to address the unmet needs of individuals with ASD and their families.

Entities receiving training initiatives grants are to expand and develop interdisciplinary training and continuing education initiatives for health, allied health, and educational professionals by engaging in the following activities:

- Promoting and engaging in training for health, allied health, and educational professionals to identify, diagnose, and develop interventions for individuals with, or at risk of developing, autism spectrum disorders.
- Working to expand the availability of training and information regarding effective, lifelong interventions, educational services, and community supports, including specific training for criminal justice system, emergency health care, legal, and other mainstream first responder professionals, to identify characteristics of individuals with autism spectrum disorders and to develop appropriate responses and interventions.
- Providing technical assistance in collaboration with relevant State, regional, or national agencies, institutions of higher education, advocacy groups for individuals with autism spectrum disorders and their families, or community-based service providers.
- Developing mechanisms to provide training and technical assistance, including for credit courses, intensive summer institutes, continuing education programs, distance-based programs, and web-based information dissemination strategies.
- Collecting data on the outcomes of training and technical assistance programs to meet statewide needs for the expansion of services to children with autism spectrum disorders and adults with autism spectrum disorders.

Two percent of the funds provided under this section will be reserved to provide a grant to a national organization with demonstrated capacity to provide training and technical assistance to those receiving training initiative grants.

Amendments Related to Health Insurance

Sec. 12 requires that health insurers cover the diagnosis and treatment of ASD, including Applied Behavioral Analysis therapy and assistive communication and other assistive technologies.

Authorization of Appropriations

Sec. 13 authorizes such sums for FY 2010 through 2014 as may be necessary to carry out the programs under the Act.

Fiscal Year 2010 LEND Appropriations Summary

Summary: Both House and Senate bills provide 28,200,000, a \$2.2 million increase to continue to enhance the capacity of existing LEND programs and to continue to expand the number of LEND sites. It is expected that the L-HHS-ED bill will be included in a small omnibus bill before the end of this session of Congress. With the \$2 million secured in both bills, it is likely that the increase will remain in the final bill signed by the President.

House Report (111-220) for the Labor, HHS, Education FY 2010 Appropriations bill

Autism and Other Related Developmental Disorders

The Committee provides \$48,000,000 for activities authorized in the Combating Autism Act, which is \$6,000,000 above the fiscal year 2009 funding level and the same as the budget request. Within the total, the Committee provides \$28,200,000 for the Leadership Education in Neurodevelopmental and Related Disabilities (LEND) program to enhance the capacity of existing LEND programs and expand the number of sites and professionals trained to diagnose, treat, and provide interventions to individuals with autism spectrum disorders. This increase of \$2,200,000 will help these programs initiate or expand their work in the area of interdisciplinary leadership training to meet the needs of children with autism spectrum disorders and related neurodevelopmental disabilities.

Senate Report (111-66) for the Labor, HHS, Education FY 2010 Appropriations bill

Autism and Other Developmental Disorders

The Committee provides \$48,000,000 for the autism and other developmental disorders initiative. The fiscal year 2009 comparable level was \$42,000,000 and the budget request for fiscal year 2010 was \$48,000,000. The program supports surveillance, early detection, education and intervention activities on autism and other developmental disorders, as authorized in the Combating Autism Act of 2006.

Within the funding provided for autism and other related developmental disorders, an increase of no less than \$2,000,000 is provided to continue and expand research on evidence-based practices for interventions for individuals with autism and other developmental disabilities, for development of guidelines for those interventions, and for information dissemination. In addition, an increase of no less than \$2,000,000 is provided to continue and expand the Leadership Education in Neuro-developmental and Related Disabilities program.

Combating Autism Act: P.L. 109-416 Section 399BB

“(e) DIAGNOSIS.—

“(1) TRAINING.—The Secretary, in coordination with activities conducted under title V of the Social Security Act, shall, subject to the availability of appropriations, expand existing interdisciplinary training opportunities or opportunities to increase the number of sites able to diagnose or rule out individuals with autism spectrum disorder or other developmental disabilities and ensure that—

“(A) competitive grants or cooperative agreements are awarded to public or nonprofit agencies, including institutions of higher education, to expand existing or develop new maternal and child health interdisciplinary leadership education in neurodevelopmental and related disabilities programs (similar to the programs developed under section 501(a)(2) of the Social Security Act) in States that do not have such a program;

“(B) trainees under such training programs—

“(i) receive an appropriate balance of academic, clinical, and community opportunities;

“(ii) are culturally competent;

“(iii) are ethnically diverse;

“(iv) demonstrate a capacity to evaluate, diagnose or rule out, develop, and provide evidence-based interventions to individuals with autism spectrum disorder and other developmental disabilities; and

“(v) demonstrate an ability to use a family-centered approach; and

“(C) program sites provide culturally competent services.

Implications of Autism and Developmental Screening in the Office Setting

Robyn Strosaker, MD, Andrew Hertz, MD
 Gabrielle Harpell, MD, Nancy Roizen, MD
 Rainbow Babies and Children's Hospital
 Case Western Reserve University School of Medicine
 Supported by HRSA T77MC 00004

Choosing Tools

- Practice Factors
 - Completion during visit, mailing, etc.
 - Interruption of work-flow
 - Cost to purchase tools
- Parent and Family Factors
 - Readability
 - Time for completion
 - Need for specific toys or tools
- Sensitivity and Specificity of the Tools

Coding

- 96110: Limited Developmental Screening
 - Can code this twice if using 2 screens
 - RVU = 0.36
 - Medicaid will pay for this
 - Private insurance may vary

Pilot Project: Pediatric Practice at Rainbow

- Pediatric Practice at Rainbow
 - M-CHAT and PEDS administered at appropriate visits
 - Primarily Medicaid HMOs
 - Initial data on percentage screened
 - Ongoing data on change in Early Intervention referrals
- Lessons Learned:
 - Most parents complete forms with little interruption to the work-flow
 - Multiple reminders for physicians and medical assistants needed
 - Quickly integrated into "standard of care"

Pilot Results: Pediatric Practice at Rainbow

- Screening audit data
 - Almost 900 PEDS administered between 3/09 and 5/09
 - 73% of eligible patients screened during initial implementation period
 - 9 month visit least likely to be screened
 - Other visits had both PEDS and M-CHAT administered

Pilot Results: Suburban Pediatrics

- Suburban Pediatrics
 - M-CHAT administered at all 18 and 24 month visits for 3 months
 - 2 office locations
 - Many insurance payors
 - Data collected on numbers of screens administered and revenue collected
- 10 weeks of data collected after initial implementation

Pilot Results: Suburban Pediatrics

- 93 patients given M-CHAT at 18 or 24 month visit
 - 93% of eligible patients screened
 - 70% of those screened were billed
- Re-imburement
 - Average insurance payment \$14.07
 - Including non-payment
 - Range of insurance payment \$10.32-\$24.21
 - 69% of insurance claims paid
 - 3.2% personal paid (insurance "carve-out")

What do I do with a positive Screen?

- **Simultaneous** Referral Process:
 - Audiology
 - Speech Language Pathology Evaluation
 - Comprehensive ASD Evaluation = Subspecialty Referral
 - Early Intervention or Early Childhood Education
 - < 3 years: Early Intervention
 - > 3 years: Local School District
- Schedule Follow-up Visit in 1 month
- Provide Parental / Family Support

Rainbow Tools

University Hospitals
Rainbow Babies & Children's Hospital

Toddler Development Questionnaire

The questionnaire consists of 20 questions. Each question has four possible responses: 'Yes', 'Probably', 'Probably Not', and 'No'. The questions are numbered 1 through 20.

1. Does your child have any of the following behaviors?
 2. Does your child have any of the following behaviors?
 3. Does your child have any of the following behaviors?
 4. Does your child have any of the following behaviors?
 5. Does your child have any of the following behaviors?
 6. Does your child have any of the following behaviors?
 7. Does your child have any of the following behaviors?
 8. Does your child have any of the following behaviors?
 9. Does your child have any of the following behaviors?
 10. Does your child have any of the following behaviors?
 11. Does your child have any of the following behaviors?
 12. Does your child have any of the following behaviors?
 13. Does your child have any of the following behaviors?
 14. Does your child have any of the following behaviors?
 15. Does your child have any of the following behaviors?
 16. Does your child have any of the following behaviors?
 17. Does your child have any of the following behaviors?
 18. Does your child have any of the following behaviors?
 19. Does your child have any of the following behaviors?
 20. Does your child have any of the following behaviors?

University Hospitals
Rainbow Babies & Children's Hospital

Toddler Development Questionnaire - Score Key

The questionnaire consists of 20 questions. Each question has four possible responses: 'Yes', 'Probably', 'Probably Not', and 'No'. The questions are numbered 1 through 20.

1. Does your child have any of the following behaviors? Yes Probably Probably Not No

2. Does your child have any of the following behaviors? Yes Probably Probably Not No

3. Does your child have any of the following behaviors? Yes Probably Probably Not No

4. Does your child have any of the following behaviors? Yes Probably Probably Not No

5. Does your child have any of the following behaviors? Yes Probably Probably Not No

6. Does your child have any of the following behaviors? Yes Probably Probably Not No

7. Does your child have any of the following behaviors? Yes Probably Probably Not No

8. Does your child have any of the following behaviors? Yes Probably Probably Not No

9. Does your child have any of the following behaviors? Yes Probably Probably Not No

10. Does your child have any of the following behaviors? Yes Probably Probably Not No

11. Does your child have any of the following behaviors? Yes Probably Probably Not No

12. Does your child have any of the following behaviors? Yes Probably Probably Not No

13. Does your child have any of the following behaviors? Yes Probably Probably Not No

14. Does your child have any of the following behaviors? Yes Probably Probably Not No

15. Does your child have any of the following behaviors? Yes Probably Probably Not No

16. Does your child have any of the following behaviors? Yes Probably Probably Not No

17. Does your child have any of the following behaviors? Yes Probably Probably Not No

18. Does your child have any of the following behaviors? Yes Probably Probably Not No

19. Does your child have any of the following behaviors? Yes Probably Probably Not No

20. Does your child have any of the following behaviors? Yes Probably Probably Not No

Rainbow Tools

University Hospitals
Rainbow Babies & Children's Hospital

Child Development Resources

Developmental Testing & Diagnosis
 University Hospitals, Rainbow Babies & Children's Hospital - 216-844-7246
 Rainbow Child Development Center Pediatric Neurology

Audiology Services
 Cleveland Hearing & Speech Center - 216-844-7246 (Multiple locations)
 University Circle - 216-221-8787 South Euclid - 216-382-4530
 Shaker Square - 216-638-1477 Lorain - 440-277-4602

Speech & Language Therapy
 Cleveland Hearing & Speech Center - 216-844-7246 (Multiple locations)
 University Circle - 216-221-8787 South Euclid - 216-382-4530
 Shaker Square - 216-638-1477 Lorain - 440-277-4602
 Achievement Centers for Children - 216-260-8700

Recommended Web sites for more information for families:

American Academy of Pediatrics www.aap.org
 Attention Deficit/Hyperactivity Disorder www.mindzone.org
 Office Center for Autism and Learning www.ccl.org
rainbowbabies.org • 216.844.8428/8700

Autism Consortium and Email Messaging Service for ASD

Leonard Rappaport, MD, MS
Chief, Division of Developmental Medicine
Children's Hospital Boston
Mary Deming Scott Professor of Pediatrics
Harvard Medical School

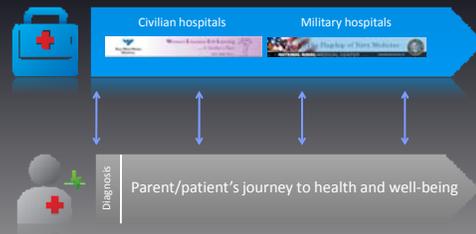


Autism Consortium

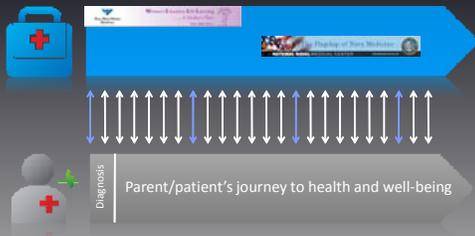
- All major institutions throughout Boston area
- Clinicians and researchers
- Funded high risk, high reward research
- Funded Resource Specialists throughout Boston through philanthropy
- Established information & resource database
- <http://www.autismconsortium.org/>
- Whetted our appetite for more contact!

Disclosure

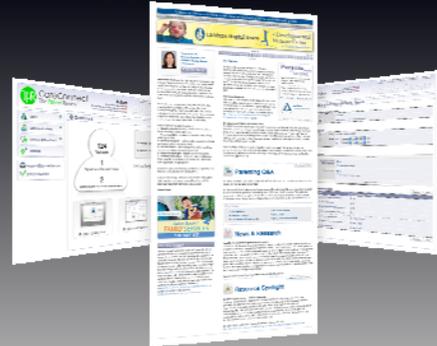
The CEO of TPR Media is my wife
and I sort of tricked her into this.



Establish care connections that matter.



Email messaging service for Autism Spectrum Disorders



A Variety of Tools to Communicate



Brand & personalize every connection



Turn-key, yet entirely customizable content solution

experts have contributed the information and content.

- Monthly content—family information about the latest research and treatments
- Parenting Q&A—answers to parents' frequently asked questions
- News & Research—cutting-edge research and new and relevant findings in the field
- Did You Know?—interesting information and how you can put it into practice in your child's life
- Research Roundup—highlighting the latest research
- & More from Autism—resources, which address DSM-5 specific questions and inform you about upcoming events and programs

News that you can read just a minute at any time, and that you can involve the at any time.

Alana Green



Processing disorders. Although no one can predict the future for any child, with or without a diagnosis of autism, the prospects are much brighter for children diagnosed today than they were even a decade ago. Examples of some advances in ASD treatment recognized at the "Development of Novel Therapeutic Approaches: The Next Steps for Autism" in 2009.



UNIVERSITY OF UTAH

Parenting Q&A

Q: "My child recently received a diagnosis of PDD-NOS and I am not sure exactly what that means. Is this the same as autism?"

A: The term PDD-NOS (now called "Developmental Disorder Not Otherwise Specified") is used to describe certain problems in development. PDDs are called "spectrum" disorders because each individual has symptoms that differ, including ranging from mild to quite severe. PDDs come under the umbrella of Autism Spectrum Disorders, as you can see in this chart.

Our links

- Our website
- Support centers
- CIS Research/Instruments
- Resource center
- DMC team
- DMC AAP Autism Guide

Promote research, programs & local resources

Autism Society
FAMILY SERVICES
100 DAY KIT

News & Research

Specific Researcher's research published in Nature. This study shows that the majority of autism cases appear to be genetic in origin. The study also shows that the majority of cases are not caused by environmental factors. The study also shows that the majority of cases are not caused by environmental factors. The study also shows that the majority of cases are not caused by environmental factors.

Did You Know?

Did you know that...? This is a section for interesting facts and tips. It includes information about the latest research and how you can put it into practice in your child's life.

Resource Spotlight

Autism Support Center of Minneapolis. This is a section for highlighting local resources and programs. It includes information about the latest research and how you can put it into practice in your child's life.

Easily build a database of your families.



Sign-up page

Children's Hospital Denver

Database

Next Steps: A Parent Support and Education Program for Families with a Child Recently Diagnosed with an ASD

Combating Autism Act Initiative Meeting

Leadership Education in Neurodevelopmental Disabilities (LEND) Training Program
Leadership Education in Developmental-Behavioral Pediatrics Training Program
The Children's Hospital of Philadelphia
University of Pennsylvania School of Medicine



The Problem

- Diagnosis of an ASD overwhelming for families
- Limited time to discuss more than the initial steps in intervention
- Families struggle to obtain needed services
- As families learn about the diagnosis many questions arise
- Distinguishing reliable and unreliable sources of information is challenging
- Trainees need to learn to give formal educational presentations to parents

Next Steps: An Opportunity for Families and Trainees

- **6 hour parent support and education program for families with a child recently diagnosed with an ASD**
 - Reliable information from interdisciplinary service providers
 - Support from providers, experienced parents and to network with each other
- **Trainees to learn**
 - To give presentations to parents
 - To learn about the challenges parents experience
 - To plan a conference with parent input

Next Steps: Schedule

- **Provided 3-4 times per year**
- **Schedule**
 - 8:00-8:30 Registration
 - 8:30 Welcome
 - 8:45 Medical Evaluation and Treatment of ASD
 - 9:15 Introduction to Special Education Rights and Processes
 - 9:45 Break
 - 10:00 Language in ASD
 - 10:30 Occupation Therapy Evaluation and Treatment
 - 11:00 Applied Behavior Analysis
 - 11:30 Lunch/Parent Support/Ask the Experts
 - 1:00 Parent /Family Panel
 - 2:30 Wrap-up/Evaluation

What Families Liked or Learned

- The tips for families with children with autism as to the best way to support them.
- Being able to identify your feeling of hurt, while dealing with your child.
- Resources made available and the parent panel. I really appreciate their experiences and knowledge.
- Autism Speaks 100-day kit and power point presentations.
- Printed material provided with presentations.
- Practical useful information for families and how to obtain services.

What Families Liked or Learned

- Learning about speech therapy procedures, links to resources.
- Specific examples of symptoms behaviors coping techniques, IEP components, etc.
- Family interaction and knowledge
- Getting perspective of parents.
- Personal stories
- Parent sharing
- That every child is different.