

**A FORUM ON AUTISM SPECTRUM DISORDERS (ASDs)
BEST PRACTICE IN DIAGNOSIS FOR YOUNG CHILDREN**



**TUESDAY, JANUARY 25, 2011
9:00 A.M. – 12:00 P.M.
LEGISLATIVE OFFICE BUILDING, 2C
HARTFORD, CONNECTICUT**

BACKGROUND

Recent research indicates that children with ASDs are not diagnosed, on average, until 13 months after their initial screening by a qualified professional (Wiggins, Bajo & Rice, 2006). This is in part due to lengthy waiting lists for diagnostic evaluations, which ultimately delay entry of children into services. Further, idiosyncratic diagnostic evaluations lead to the need for the replication of an evaluation and unnecessary cost and time expenditure, as well as increased worry for parents when both false positive and false negative diagnoses are generated. In order to streamline the diagnostic evaluation of children with suspected ASDs, states have developed standardized yet flexible approaches to evaluating children and have defined acceptable approaches to diagnosis within their state. The Centers for Disease Control & Prevention have developed *Autism A.L.A.R.M. Guidelines*, which provide a surveillance and screening algorithm and lay the foundation upon which the work of the Connecticut team will be based. In addition, Missouri and California have convened working groups to define best practice within the context of existing resources so that children who qualify for ASDs diagnosis can move quickly into receiving intervention.

In 2007, a partnership was formed between the National Center on Birth Defects and Developmental Disabilities (NCBDDD) at the Centers for Disease Control and Prevention (CDC), the Maternal and Child Health Bureau (MCHB) at the Health Resources and Services Administration (HRSA) and the Association for University Centers on Disabilities (AUCD) to implement the “Act Early” Regional Summit Project. The vision of the project, supported by the *Learn the Signs Act Early Campaign* and the Combating Autism Act, was to bring together leaders from the early intervention and early childhood community for the purpose of enhancing relationships and collaborations between key leaders in the state.

THE CONNECTICUT PICTURE

The 2005-2006 National Survey of Children with Special Health Care Needs (CSHCN) estimated that approximately 133,073 children in Connecticut, ages 0-17, have special health care needs, representing approximately 16% of all children in the state. As of March 31, 2010, a total of 7,766 out of 9,043 children in the Children and Youth with Special Health Care Needs (CYSHCN) had been specifically diagnosed, with 1,001 having Autism, Pervasive Developmental Disorder, or Asperger's as the primary diagnosis. The data indicates that 13% of CYSHCN consumers with a specific diagnosis in the database have ASDs, making it the single largest diagnostic group receiving services. Furthermore, the prevalence of children being diagnosed with ASD in Connecticut in 2000 was 1,377 students or 1.86% of children ages 3-21. This figure indicates a dramatic rise in the rate of prevalence of 6.36% for 2007-2008, or 4,387 children ages 3-21 (Easter Seals, 2009).

Birth to Three

Early intervention services or Birth to Three (Part C under IDEA) in Connecticut is administered by the Department of Developmental Services. There are currently a total of forty-four Birth to Three programs in Connecticut, including nine Autism specific programs. From July 1, 2009 to June 30, 2010, Birth to Three served 9,591 children and families, including approximately 600 children between 1-2 years old with ASDs. One out of every 166 two year olds in Connecticut provided with Birth to Three services was designated as having ASDs.

Preschools

Services provided for preschoolers (age 3-5) (Part B under IDEA) with ASDs in Connecticut include a variety of services and service models individually administered by local school systems. For the period of 2007-2008, a total of 587 out of 7,660 students in Part B preschools had a diagnosis of ASDs (OSEP, 2007).

GOAL OF THE ACT EARLY CONNECTICUT TEAM

The Connecticut Team developed the following overarching goal during the Summit:

In order to assure valued life outcomes, all of Connecticut's diverse families (urban, suburban and rural) and other stakeholders will be aware of the early signs of Autism Spectrum Disorder and have knowledge about, and access to, evidenced based, individualized, and timely screening, diagnostic assessment and interventions as implemented by a competent work force and funded, coordinated system of care.

The Team decided to focus on two main areas to achieve this goal: Developing Best Practice Guidelines and Raising Awareness.

Learn the Signs.
Act Early.



CONNECTICUT'S ACT EARLY PLAN

Developing Best Practices Guidelines

The Act Early Connecticut Best Practices group intends to engage in the following activities toward the development of diagnostic guidelines: convene a legislative forum, develop a draft document of the proposed guidelines, disseminate the draft guidelines to an expert panel, including members of the Act Early Connecticut Team, and print and distribute the guidelines. As a result of developing best practice guidelines for a diagnostic evaluation of ASDs that is recognized and implemented by providers, the care of children with developmental delays will be streamlined. With children more accurately diagnosed at an earlier age, access to intervention should occur in a more timely fashion.

Raising Awareness of the Need for Early Screening, Diagnosis and Intervention

The Awareness Team's efforts have centered on disseminating the CDC "Learn the Signs, Act Early" campaign materials at conferences and through a targeted mailing campaign. Materials from the CDC on recognizing developmental delays along with Connecticut-specific information will be sent to core groups throughout the state: medical providers, licensed family day cares, and licensed group day care centers, including nursery schools. Data provided by the State Department of Health indicates that there are 2,687 Family Day Cares and 1,589 Group Day Cares, for a total of 4,276 facilities. This represents a total of 113,734 children potentially being served with information on early identification of developmental delays in Connecticut. Data on whether additional material is requested will help to determine the effectiveness of the process and indicate whether further targeted mailing should be implemented. With children accurately identified as potentially at risk, access to early intervention might decrease the long term effects of any delays.

PARTICIPANTS

African Caribbean American Parents of Children with Disabilities

A.J. Pappanikou Center for Excellence in Developmental Disabilities, Education, Research and Service

Autism Spectrum Differences Institute of New England, Inc.

Autism Spectrum Resources Center, Inc.

Children and Youth with Special Health Care Needs Program of the Connecticut Department of Health

Community Renewal Team

Connecticut Chapter of the American Academy of Pediatrics (AAP)

Connecticut Children's Medical Center

Connecticut's Birth to Three System of the Department of Developmental Services

Department of Developmental Services

Families of Children with ASD

Hospital for Special Care

Office of Protection and Advocacy

River Street Autism Program at Coltsville

Riverview Hospital for Children and Youth, Department of Children and Families

State Department of Education

The Center of Excellence on Autism Spectrum Disorders, Southern Connecticut State University

Yale University's School of Medicine's Developmental Behavioral Pediatrics Program

RESOURCES

Links to Missouri and California Best Practices Websites

Missouri Department of Mental Health, Division of Developmental Disabilities (2010). Autism Spectrum Disorders: Missouri best practice guidelines for screening, diagnosis, and assessment: www.autismguidelines.dmh.mo.gov

California Department of Developmental Services (2002) Autism Spectrum Disorders: Best practice guidelines for screening, diagnosis and assessment. Sacramento, CA: www.dds.ca.gov/Autism/docs/ASD_Best_Practice2002.pdf

The CDC, through its Learn the Signs, Act Early initiative, has material available to the public at no cost. Either downloaded directly from the internet or sent through the mail, this information is designed to educate parents, pediatricians, early care providers, and other professionals on the need for early diagnosis and the potential presence of developmental delays. Please browse through the website for material that might be of interest at: www.cdc.gov/ncbddd/actearly/downloads.html

Contact information

For more information about Act Early Connecticut, to reach any member of the initiative or one of today's speakers, please contact Tierney Giannotti at tgiannotti@uchc.edu or at 860.679.1516. For additional information, you may also visit these websites:

University of Connecticut's LEND Program:

<http://www.uconnucedd.org/lend/newsandevents.html>

Association for University Centers on Disabilities (AUCD):

<https://www.aucd.org/template/index.cfm>

Centers for Disease Control and Prevention (CDC):

<http://www.cdc.gov/ncbddd/actearly/index.html>

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