

Diagnosis and Screening
7/16/08
Meeting 1

In attendance: Jennifer Muller, (Autism Society of America), Rep. Cam Ward, Dr. Felicia Houston (Glenwood), Dr. Hanes Swingle, Chairman (USA), Dr. Karen Dahle (UAB Special Education), Art Dahle, Linda Lee (AL Chapter of the Academy of Pediatrics) here on behalf of Dr. Myriam Peralta, Cheris LeMay (Public Health); Kathy Welch (Easter Seals); Laura Klinger (U of A-Tuscaloosa), Elizabeth Schneider (Easter Seals).

Welcome from Hanes Swingle, Chairman

Rep. Ward gave the charge to the group reminding us that government works slowly. We are charged with coming up with a series of final recommendations to present to the Governor and the Legislature in February 2009. Last year one of the recommendations was the development of the IACC to bring all agencies together, which has been accomplished.

The challenge for the Diagnosis and Screening subcommittee is to make sure children are diagnosed early. Rep. Ward reminded us of the state budget and its limitations. Subcommittee recommendations should be made regardless of the money needed for their implementation. Monies are being put into the Autism Council now. A written final report will be needed from each subcommittee. The Diagnosis and Early Screening sub-committee needs to direct its efforts to diagnosis and screening. A question was asked about the availability of Federal Funds. Designated Federal Funds for autism will likely be available in the future, but State Funds will be needed to match these funds. A question was asked about the Alabama Autism Collaborative Group (AACG). The AACG is the group that was charged to complete the Needs Assessment. AACG has worked closely with the Autism Task Force. The recommendations of both groups overlap and share a common goal.

Hanes mentioned that Alice Widgeon and Betsy Prince are also members of this sub-committee, but were unable to attend today due to scheduling conflicts. Dr. Norma Davis, a Developmental Pediatrician in Montgomery, and Dr. Angie Barber, speech and language pathologist at the University of Alabama, will also be members. Rep. Ward offered to assist the sub-committee in getting a representative from the Medical Association of the State of Alabama (MASA).

Hanes would like for our goals to be specific and prioritized. He reviewed the preliminary recommendations of the Autism Task Force regarding screening and diagnosis. One recommendation is for the awarding of grants for Advocacy programs to raise autism awareness. A literature review to determine which awareness programs have been proven to be effective is planned. Dr. Swingle suggested that early identification of children with autism does not need to be restricted to physicians. Many day care providers spend a large amount of time observing children's behaviors and could assist

with identifying those children at risk for autism. Children who have qualified for Early Intervention services due to developmental delay are an exceptionally high-risk group that would benefit from autism screening. All physicians need to be aware of the signs of autism, not just pediatricians. Ms. Welch pointed out that some children are only seen by healthcare workers at Public Health Clinics or in Emergency Rooms. A question was asked if there is a specific screening test for autism that healthcare workers should use. The American Academy does not recommend any one test.

Dr. Laura Klinger spoke about the Alabama Autism Collaborative Group and its make up. She spoke of the Literature Review of Best Practices. The full report is available at Cam Ward's website (www.camward.com) and on the Autism Society's website (www.autism-alabama.org). Dr. Klinger highlighted the delay from when parents are first concerned and the time when the children are actually referred. According to CDC data children aren't usually diagnosed until 4 nationally but in Alabama our children aren't diagnosed until 5.5 years of age. Diagnosis depends on what type of Autism Spectrum Disorder you have. There is good evidence that intervention before 3 results in better outcomes than after that.

The American Academy of Pediatrics recommends Autism specific screening at 18 months and again at 24 months of age. The Academy of Neurology recommends use of a broadband screener, to be followed by an autism specific screener only if a child has certain red flags. The AACG Needs Assessment reviewed the Ages and Stages Questionnaire, which is a broadband developmental screening test, the M-CHAT, which is an autism specific screener completed by parents, and the CSBS, a broadband screener, which focuses on language and social delays. None of the data regarding any of these screeners is complete. Dr. Klinger feels our sub-committee should recommend the screening tests to be used by healthcare workers seeing young children. It would be helpful to pick an instrument and evaluate its effectiveness. A question was asked about parents who aren't aware enough to ask for or fill out the screener.

There was discussion about developing a tiered screening process. Dr. Klinger suggested that a level II screener, such as the STAT (Screening Tool for Autism in Two year olds), could be used by Early Intervention. Early Intervention (EI) would need training to perform these screenings, which Regional Autism Centers could provide. It was noted that some Early Intervention trainers have only graduated from high school and have had limited training. The Regional Centers should assist in the training of EI professionals.

Dr. Dahle addressed the preschool perspective. Dr. Dahle pointed out that a clinical diagnosis of autism does not translate into school eligibility. For children ages 0-2 years there is not a diagnosis for autism and the only one available is Developmental Delay. At age 3 you can qualify with autism or with developmental delay. The schools can maintain the Developmental Delay (DD) diagnosis and eligibility until age 9. In rural and many urban areas, many children with autism are labeled as DD.

Many physicians do not refer to EI. If a child is seen by EI and doesn't meet eligibility, i.e., $\geq 25\%$ delays, the family may have the false perception that the child is

okay. There was general agreement that if EI is to be a tiered piece of the system to be developed, training of EI staff by Regional Centers will be necessary.

Early Intervention only serves children up to age 3. Diagnosis of children older than 3 needs to be addressed in this committee. We need to talk about capacity in the current clinics when thinking about Regional Centers. One proposed solution for addressing rural versus urban disparities in diagnostic services was the development of satellite clinics by our Regional Centers. In the early ages you can get services without the diagnosis.

Alabama has just changed a standard regarding child eligibility. We now need to evaluate a child in an unstructured environment. That has always been part of the Federal Law and is now in Alabama's law.

The sub-committee needs to think about children with Asperger Syndrome and their needs regarding diagnosis. They are currently working on the DSM-V. None of our instruments right now can accurately differentiate between Asperger's syndrome (AS) and High Functioning Autism (HFA). It is very difficult to diagnose AS with the current DSM. AS often get diagnosed with OCD, Anxiety, and Depression first. There is the CAST (The Childhood Asperger Syndrome Test), but the group had reservations about this screener.

The research shows that an experienced clinician can reliably diagnose at age 2. In terms of interventions, there are recommendations specific for autism. The ADI is all based on past behavior. There was talk of provisional diagnosis, follow up evaluations, etc. It was noted that when children do better, their supports/services are often removed.

A discussion centered on the proposed changes to the term for the initial IEP evaluation period. ADAP's paper was circulated to the group and we discussed the period for public comment. A teacher with significant experience can make the diagnosis according to the law. Over 400 diagnostic evaluations were done by Glenwood in the school systems. Dr. Swingle mentioned that some schools appear reluctant to use diagnostic resources available from Glenwood and diagnosis a child with HFA or AS, due to the increased expenses the schools incur after a child is diagnosed. There is a trend of schools training their own people to do the ADOS. Kathy Lord, who developed the ADOS, stressed that clinical experience is critical when using this diagnostic instrument. We need to think about recommendations that will address these issues.

The Diagnosis and Early Sub-committee will meet monthly. These meetings are tentatively scheduled for 10:00 AM on the third Wednesday of the month. Our next meeting will be August 20th at 10:00 in Room 123 of the State House. We will hear from Alice Widgeon and from Angie Barber. Hanes Swingle will review public awareness strategies that have been shown to be effective. We discussed needing to look at both Autism Specific Screening tools and General Pediatric Screeners. A chart that compares the screening tools would be helpful. The AAP reference by Chris Johnson has a chart comparing screening tools and will be brought to the next meeting.