

Alabama Interagency Autism Coordinating Council
Monday, February 2, 2010
Alabama Institute for Training and Development

The Alabama Interagency Autism Coordinating Council met on Monday, February 2, 2010 at the Alabama Institute for Training and Development (AIDT). The meeting was called to order by the Chairman, Representative Cam Ward. Representative Ward asked that each person on the council state their name and who they represent. After the introductions, Dr. Caroline Gomez performed roll call. The Autism Council members in attendance are as follows: Representative Cam Ward, Dr. Bama Hager, Dr. Hanes Swingle, Julie Brown, Dr. Sandra Parker, Tristan Dunn, Kathy Welch, Evan Krchak, Jim Mercer, Dr. John Langlow, Melanie Jones, Linda Bacchus and Dr. Myriam Peralta. The following proxies were in attendance as well: Kim Hill, representing Dr. Cary Boswell, Kaye Melnick, representing Carol Steckel, Dr. Mabrey Whetstone representing Dr. Joe Morton, Dawn Ellis representing Dr. Don Williamson, Tonya Trim representing Marquita Davis, Sue Berry representing Nancy Buckner, Elizabeth Griffith representing Dr. Fred Biasini, and Alice Widgeon representing John Houston.

Representative Ward then recognized Alice Widgeon as Commissioner Houston's representative and asked if she would like to share any comments on the Department's behalf. Ms. Widgeon stated that the Commissioner regretted not being able to attend the meeting, but that Dr. Gomez has kept him updated on the activities of the Council and he is very enthusiastic about the progress and is looking forward to the outcomes.

The minutes from the October 26, 2009 meeting were introduced and approved.

Representative Ward commended those who have served on the various committees that have been created. He said that these committees will pay off in the long run and asked if others are interested in serving to please let a member of the Council know.

As the chair of the Standards of Practice Committee, Alice Widgeon stated this is a standing committee of the group which will be determining best practices. There are now leaders for all the groups except one. The workgroup leaders are: Diagnostic Clinics – Dr. Hanes Swingle; Birth to 5 Services – Still looking for a Chair; Services 6-21 years – Abbie Felder; Transition Services – Dr. Jennifer Sellers; Adult Services – Dr. Jade Carter; and Professional Preparation Training – Dr. Doris Hill. Ms. Widgeon mentioned she would like to have the Chairs get together for a meeting soon, perhaps by conference call.

Representative Ward announced that Kim Hill will be the Chair of the By-Laws Committee. He also announced that the new Special Projects Committee will be chaired by Melanie Jones.

Ms. Jones shared that the Council has distributed a survey, and based on the responses, individuals were placed in four different work groups. The first group, Awareness, will be led by Tuwana McGee of ADAP. The Awareness group consists of

12 members. Their first task will be the Lifespan Resource Tree. Those resources will then be shared on the AIACC website. The second group is Community Services which will be led by Anna Bloom of the Autism Society of Alabama. This group consists of 11 members. The first task of this group will be First-Responders Training. The third workgroup is Family Supports which will be led by Jennifer Robertson. This group has 16 members and will focus on respite care resources. The final group is Developmental Surveillance and Early Screening which will be led by Dr. Sara O'Kelley. This group has 24 members. They will use the "Learn the Signs - Act Early" materials that are already available from the Center's for Disease Control and Prevention to head up the campaign efforts.

Ms. Jones also announced that the Autism Legislative Day will be March 25th, at the Alabama Statehouse. Clients should be encouraged to attend. Representative Ward shared how important an opportunity this is as it has a stronger impact on policy recommendations than anything else.

Dr. Bama Hager is the Chair of the Strategic Planning Committee. Dr. Hager submitted a draft of the Mission Statement of the Council, as recommend by her Committee which reads:

The mission of the Alabama Autism Interagency Coordinating Council (AIACC) is as a collaborative body to develop guiding principles to facilitate a state-wide, comprehensive, coordinated, multidisciplinary, interagency, life-long system of care for persons diagnosed with Autism Spectrum Disorders, their families, communities and public or private agencies and to support persons living on the Autism Spectrum to meet their fullest potential and enjoy a meaningful and successful life.

A motion was made to adopt the Mission Statement as presented, and the motion was carried.

Dr. Hager also mentioned a project she is working on which is a Glenwood Planned Community for adults with ASD. She introduced the Glenwood Housing Interest Survey, developed by Saundra Ivey. Surveys were distributed to those at the meeting who chose to participate. Additional surveys will be distributed to parents over the next few months.

Dr. Hager also announced that Ms. Melanie Jones is now the Executive Director of the Autism Society of Alabama, a position formerly held by Ms. Jennifer Muller.

State Coordinator, Dr. Caroline Gomez, stated the Final Legislative Report was presented to the Governor and Legislature before the deadline on January 22nd. A copy was provided to Council members in their packets.

Dr. Gomez reported that over 130 individuals responded to the Interest Inventory Survey used to staff the Committees. Dr. Gomez asked that if anyone is interested in participating on a Committee, to please let a Council Member know.

Also provided to the Council Members was a list of Strategic Planning Committee Guidelines and Resources. This is intended to assist the committee in locating resources for their efforts. In addition, a Committee Meeting Agenda and Action Plan that will be used to document every Committee or Workgroup meeting was provided.

Dr. Gomez shared with the attendees, the AIACC website, www.autism.alabama.gov. Dr. Gomez acknowledged the hard work of Peggy Olson with the Department of Mental Health who was the web designer. Information included on the site is a listing of the Council Members, Member Agencies, Minutes of the Meetings, Documents including all the legislation, and any other documents deemed important. Also included is a Plan of Action: A Work in Progress. The ultimate goal is to have a total system of care for our State.

Alice Widgeon made a recommendation that Dr. Bama Hager be made Co-Chair of the AIACC. The motion was seconded and carried and the appointment was accepted.

Programs presented at the meeting were the USA Autism Clinic and Alabama Lifespan Respite Resource Network. The first individual to speak was Dr. Hanes Swingle from the USA Autism Clinic in South Alabama. Dr. Swingle shared some background on the University of South Alabama including that the College of Education has educated over 15,000 teachers and school administrators. The USA College of Medicine and Teaching Hospitals have educated and trained over 2,000 physicians, which comprises over one-third of the physician workforce in South Alabama. The Autism Diagnostic Clinic opened in April of 2007. The staff of the Clinic includes two Developmental Behavior Pediatricians, Dr. Swingle and Dr. Stephanie Anderson. There are two Psychologists on staff, one of whom is Dr. Hannahan. Their Speech and Language Pathologist is Amy Mitchell, who is also the Clinic Coordinator. They perform Multi-disciplinary Evaluations and have an Occupational Therapist and Medical Geneticist on staff. They do not have a Social Worker, however, Dr. Swingle's secretary, Judy Callahan does a great job filling that role.

During the first two and half years, the clinic has averaged a little more than 15 new patients per month. This number is expected to grow since the addition of Dr. Anderson to the staff. In this time, 182 children have been diagnosed with autism and they have seen another 30-40 who were diagnosed elsewhere. A problem that needs to be addressed is that only 28% of the referrals to this clinic are African-American, which is not proportional to the over 40% of the population of South Alabama which is African-American. They are aware of the disparity and the need to address it. The majority of the African-American children who come to them are referred by the USA General Pediatric Clinic, demonstrating the USA Clinic is trying to address the problem, but more referrals need to come from other sources which are not doing developmental screening such as that done by the USA General Pediatric Clinic.

The real focus of the autism clinic is early identification of children with ASD. The earlier the identification is made, the better the outcome.

Dr. Swingle stated that autism is a pattern of behavior and once that pattern is identified, it is easier to recognize it again and again. Therefore, diagnosing autism is the easy part.

After the diagnosis, the clinic does a lot of case management. The first thing they do is sit down with the family and review the child's strengths and emphasize good prognosis factors. They answer any questions the parents might have and provide links to resources. Every parent also gets a copy of the AAP booklet *Understanding Autism*. All parents are advised to contact the Autism Society to be added to their e-mail list, and to be connected with the parent support group.

All children are referred for private speech and occupational therapy in addition to Early Intervention. Children three years old and older are referred to the Little Tree Preschool. Little Tree is the premiere model preschool for children on the autism spectrum. It is the best program for children with autism. They also recommend parents contact United Cerebral Palsy and Goodwill Easter Seals. All parents are advised to apply for SSI as the child has a significant disability that is not expected to resolve in the next twelve months. This will meet the requirement for the medical component of SSI.

All children are referred to Altapointe or Baldwin County Mental Health Center. Staff at these offices can work with the child and parents to help reinforce basic behavioral management strategies. Children are also referred for nutritional counseling.

Parents are also encouraged to take care of their own mental health needs. Many parents will contact their own physicians or mental health providers.

After diagnosis, follow up is usually done after three months to make sure services have been accessed and to answer any questions the parents may have. Then children are usually seen every six-twelve months.

A big part of what they do is teaching. The staff provides a number of didactic lectures to medical students, occupational therapists, speech therapists, physician assistants, etc. They also speak in the community to increase awareness and understanding of autism. In addition, any service provider in Mobile is invited to come to the clinic to observe what they do.

The most common questions Dr. Swingle receives are: What is autism; What causes it; and How is it treated? The short answers are autism is a pattern of behavior that has a neurological basis. There is not one cause for autism. There are over sixty medical conditions associated with it. But it does have strong genetic and environmental factors. Autism is primarily treated with proper behavioral management and education.

The main focus of the clinic is diagnosis and the effective training of the next generation of physicians.

The second individual to address the Council was Java Bennett. Java is the Director of Respite Services for Alabama Lifespan Respite Resource Network. Alabama Respite has been around for ten years. Respite care is a short temporary break for caregivers of the disabled and those with chronic illnesses. After the first three years, which were funded by a grant, UCP of Huntsville kept the program going with fund-raising dollars and gave the opportunity for the program to pursue long-term funding.

Alabama Respite's mission is to make respite resources more available and easily accessible for Alabama families and caregivers of children and individuals who have disabilities or health care needs. They started off as a children's program, but as of 2005 are lifespan.

Individuals may visit the Alabama Respite website at www.alabamarespite.org for a listing by county of respite providers. Alabama Respite provides technical assistance to help people in the community come up with different ideas about what respite could be available in their community. They provide voucher respite through funding by the Department of Mental Health for adults and children. Additional respite funding is provided through HEARTS via Children's Trust Fund. All UCP Centers in the state have a HEARTS respite program. These programs are a respite opportunity for families with children on the spectrum who are 19 years of age and younger. These individuals may also qualify for the DMH respite which is lifespan. An intellectual disability is required to qualify for that program.

Last year the program served a little over 600 families with a little fewer than 15,000 hours of respite. These numbers do not include those served through other programs such as other HEARTS programs, Medicaid, the Alabama Department of Senior Services and more.

In Shelby and Jefferson counties, several people have been asked over the last few years to join the Sharing the Care project which has been piloted in Limestone County successfully. This project would bring various members of a community together to evaluate the availability of respite in the community and how access could be improved.

Ms. Bennett asked for additional help with their workgroups and welcomed anyone interested in helping with this important work to contact them to find opportunities to serve.

Representative Ward thanked Ms. Bennett for her comments and reiterated the importance of Lifespan Respite services. He also stated that anyone interested in presenting at the next Council meeting should contact himself or Dr. Gomez for that opportunity.

Additional announcements included Melanie Jones, who reminded the group of the Autism Conference, April 26th, that April is Autism Awareness Month, and Legislative Day is March 25th. The Autism Society will host fourteen walks throughout the state, and participation is encouraged. Additional information is available on the Autism Society's website.

Tom Holmes of the Arc of Alabama invited everyone to attend the Stop the Wait Rally at the Alabama Statehouse, March 3, 2010. Also Mr. Holmes shared that the Alabama Council on Developmental Disabilities has grants available to help parents and groups attend Legislative Day and other state events.

Tracy Cron shared that HBO will be airing a movie about the life of Temple Grandin on February 6th at 8:00 p.m. Eastern. Ms. Grandin is an individual with autism who has been a pioneering advocate for autism and autism spectrum disorder education.

Dr. Gary Edwards, Executive Director of United Cerebral Palsy commented that the latest budget did not include an increase for Early Intervention (EI). While the number of children served has increased by approximately 100 per month, they are being served with the same amount of money as ten years ago. Therefore, a campaign has been started to inform legislators of the importance of EI Services. Dr. Edwards asked that if anyone would like to subscribe to their e-mail list to please contact them to do so.

The next meeting of the AIACC is scheduled for Monday, April 26th, in the same location, at AIDT.

With no further comments from the floor, the meeting was adjourned.