

## Medical Home Telephone Conference May 24, 2005

Practical issues in referring and insuring adequate support for children diagnosed with autism presented by Judith Ahrano, MD (Child Development Clinic).

Over the past couple of years there has been a heavy referral for children with autism. We will look at what services are children receiving and how best to help with that.

To begin Judy started with a story that just happened to her when she was at clinic. She was over where the children play while waiting to be seen, and she saw a mother sitting with her child and she thought they looked familiar. After talking to her she realized the mother had previously been in the clinic several years ago with some of her other children, three which have been diagnosed with ASD. One of the children had behavioral issues but left the CDC clinic which meant they had missed a diagnosis of Aspergers syndrome that was recently made. Judy apologized for the added stress she may have put on the mom at the time they were coming to the CDC clinic. Since this experience Judy has become aware that it is really important to really listen to the parents and really believe what they say and not try to second guess or talk them out of it. It's important for the physician not to have his/her own agenda.

The question was asked what further evaluations should children have once a diagnosis of ASD is made. It is very important to get estimate of cognitive potential. Usually children have more than they appear to have. It is important to follow the child along and re-test and re-evaluate over time. This guides your goals and gives you a predictive value of how the child will be long term. All children diagnosed with autism should have some baseline cognitive testing. CDC is only one place this can happen, there are other recourses for tests such as U of U, PCMC and private psychologists.

What about families that want to hurry up then have to wait for services and feel frustration? They may be getting some school support but they may not have enough funding for private speech. Problems like these require a team approach. CDC has a team on site that helps deal with financial support and offers help with Medicaid eligibility. Having someone knowledgeable about financial services can be very helpful. It works really well to have OT, Psych and speech/language therapist communicate with each other. Other sources include the Autism Clinic and the Neurobehavioral Clinic.

Question by Dennis O'Dell – What tools can be used for diagnosis of Autism? CSHCN uses the ADOS, they previously used CARS and CHAT, but more people in the school systems are trained on the ADOS. Logan uses ADI, and wanted to know which is better the ADI or ADOS. Judy said the ADOS works

well for children because it's broken into different modules for different ages, it is also a play-based assessment which means you see more coming from the child themselves rather than an interview. CSHCN has also used the Aspergers Syndrome Questionnaire which has been standardized. Some schools do rating scales and sometimes you will find that each scale produces a different rating, it is important to use the history and physical information.

Question by Dennis O'Dell – What if there aren't any abnormalities on the exams do you do any medical testing?

Judy uses an MRI for child that may have delayed motor problems and large or small head size, usually produces a low yield. Look at genetic, metabolic, thyroid, celiac disease may have a higher incidence of ASD. Look at family history, medical history, and exam to guide your evaluation.

There are other services offered outside the Wasatch Front area such as Psychologists through Bear River Mental, parent group, CPD (not at expertise level), LINCS (Sherilyn Rowley, 877-335-4627 or 281-4425). Each school in the state is supposed to have an autism team.

Question by Lisa – There is an 18 year old boy who has Autism his father has pretty much kidnapped him state and police won't help the mother because of his age. Mother needs legal representation. What should MH do in this situation? Call the Utah Guardianship Association and refer mother to legal council.

Dealing with dual language and getting services for children with Autism. The language creates a problems deciding if problems are coming from autism or language. Guadalupe Center may be of help with this, they have a preschool and counselors.

Will circulate a list of services for children with Autism, can also be found on the MH website.

Will continue to focus on recruiting families for Dr. Hobson's focus groups.

Next Phone Conference is on Tuesday June 28, 2005.

Attendees: Lisa Samson-Fang, Gina Pola-Money, Barbara Ward, Judy Ahrano, Dennis O'Dell, Grace Baugh, Lisa Lee, Chuck Norlin, Diane Behl, Wendy Hobson, Robert Terashima, Darlene Pead, Val Jones, Kendra Tortalita, Gladina Yanito, Donna, Fred, Lois.