

Autism ABCs

An Education Program for Caregivers of Children with Newly Diagnosed Autism Spectrum Disorders

Lori Krasny, M.S., CCC-SLP, The Children's Center, Salt Lake City, Utah

April 18, 2008

This project created a caregiver education series for families of children with newly diagnosed autism spectrum disorders. The purpose of this program is to provide information on key topics that will assist families in understanding their child's diagnosis and intervention options. The goals of the program are: to provide information and support to families; to help families develop personal goals related to the ongoing care of their child and family; to increase self-efficacy in achieving those goals; and ultimately to decrease family stress and improve child outcomes.

Introduction and Overview

"When a child is diagnosed with autism, his or her parents are often left feeling overwhelmed and confused about what to do next and where to turn for help." -Peter Bell, Autism Speaks

Autism Spectrum Disorders (ASD) are considered one of the most common developmental disorders in the United States. In Utah, recent surveillance data has revealed that 1:166 children have an ASD (ADDMN, 2007). Families receiving this diagnosis are often overwhelmed and without adequate support may seek misleading or inaccurate information (Rhoades, et al., 2007). Furthermore, addressing the core deficits in social emotional development, behavior and communication may require expertise from many disciplines to support the complex, individual needs of a child with an autism spectrum disorder. Caregivers receiving information and support early in their child's diagnosis may be better equipped to access needed services and resources, potentially resulting in better outcomes for their children and families (Myers, et al 2007). My own clinical and personal interactions with children with autism spectrum disorders and their families has confirmed the need for this resource.

The goal of this project was to develop a resource for families and caregivers new to the arena of autism spectrum disorders. Following a diagnosis, families are often left to their own devices to understand and access information and resources. This journey may be significantly streamlined if families and caregivers receive quality support and information at the onset. In this program, information developed by Utah experts in the field of autism was compiled into a ten-hour education program presented in five, two-hour sessions. Each session addresses key topics and is developed by at least two different individuals with specific expertise in those areas. The developers of each module are from at least two different agencies, thus representing a wide cross-section of professionals, agencies and organizations that serve individuals with ASDs in Utah. Each session offers participants an opportunity to receive information, ask questions, problem solve, and offer perspectives and support to the other participants. Caregivers are asked to formulate goals they hope to accomplish as a result of the information acquired. These self-

directed goals, along with pre-and post intervention questionnaires are used to evaluate the effectiveness of this program.

Program Overview

The content of this training represents key topics in understanding the diagnosis and treatment of autism spectrum disorders. The modules are presented as follows:

Module 1:

Family Strength and Survival - parents focus on the strengths, needs and resources shared by their entire family.

Understanding Autism – parents learn to understand their child’s autism diagnosis, how the underlying deficits affect behavior and development, and what current research reveals about the diagnosis.

Module 2:

Behavioral Challenges and What To Do – parents are helped to analyze their child’s behavior, the underlying triggers and the possible function of maladaptive behaviors. They also learn strategies to minimize difficult behaviors.

Module 3:

Interventions: Traditional, and Complimentary/Alternative Treatments – parents review both traditional and complementary/alternative therapies and learn how to best evaluate the merits of a given therapy.

How To Be an Intervention Consumer and Effective Advocate- parents receive information to assist them in being informed consumers and effective advocates for their children.

Module 4:

Communication and Sensory Integration - parents learn about communication challenges and interventions specific to autism spectrum disorders. Associated challenges in sensory processing are addressed and parents learn how to incorporate a sensory diet to promote positive behaviors.

Organizing Resources – parents are offered systems and strategies for organizing and maintaining their child’s records and materials.

Module 5:

Educational Services and Community Resources - parents learn about educational services and procedures. They also learn about community resources and referral sources for finding needed supports.

Parent panel – participants have the opportunity to hear from and interact with parents active within the autism community who have children ranging in age and ability.

The development of these modules was made possible by the involvement and/or support and encouragement of the following agencies: The Autism Council of Utah, Baby Watch, The Children’s Center, Intermountain Health Care, Spectrum Academy, University of Utah Department of Pediatrics, University of Utah Department of Psychiatry, University of Utah Neurobehavior HOME Program, Utah Department of Health, Utah Families for Early Autism Treatment, Utah Family Voices, Utah Parent Center, Utah State Office of Education, Utah State University Center for Persons With Disabilities.

A flier was developed to advertise the Autism ABCs Caregiver Education Program. This flier was disseminated to local providers offering diagnostic, intervention and medical home services.

Caregivers interested in attending called to provide demographic information as well as the diagnosis and date of diagnosis of their child. Capacity for up to 15 families or 30 people is available for the initial pilot, with up to two people per family participating. Childcare will be provided for those requiring it to attend. The pilot training is tentatively scheduled for June 2008, pending presenter were diagnosed within a determined period of time (e.g., 6 months or 1 year) will be given first opportunity to enroll.

Evaluation

An IRB proposal was developed in collaboration with Paul Carbone, M.D., a former URLEND trainee and pediatrician specializing in autism spectrum disorders. It was submitted and approved by the University of Utah IRB. We hypothesized that the five-week autism education program would: (1) decrease caregiver stress, (2) increase caregiver self-efficacy in managing a child with an ASD, (3) increase social capital within the group of caregiver participants, and (4) decrease caregiver perceived developmental and behavioral concerns.

To quantitatively measure these goals, we will be conducting a prospective cohort study using pre and post intervention measures. Participants will be asked to complete a baseline questionnaire prior to participation in Autism ABCs and a follow up questionnaires three months after completing the program. The questions included are from previously published studies measuring similar outcomes. The questionnaire will be anonymous and confidential and no linkage will be made between answers and identity. The pre-intervention questionnaire will consist of four sections: 1) Demographics; 2) The Parental Concerns Questionnaire (PSC) - a brief screening checklist assessing the presence and severity of 13 developmental and behavioral concerns expressed by parents of children with autism spectrum disorders, ages 4 to 10 years with a clinical diagnosis of autism spectrum disorder (McGrew, 2007); 3) The Aggravation in Parenting Scale (APS) - a measure of parenting stress designed for parents of children 4 – 17 years (Shieve, 2007); 4) The Social Capital Scale for families raising children with chronic health conditions (SCS) - five subscales that provide insight into family strengths and areas for improvement related to their investment in relationships that support health.

At the completion of each of the five sessions, program participants will be asked to develop one goal, based on the content of that module, that they believe they can make progress on over the next three month period. Caregivers will be encouraged to interact with the group to identify these goals. At the end of the entire program each participant will be given a list of the five goals they identified for themselves over the five modules. These same goals will be provided to the participants three months following the program, to evaluate the progress made on each goal.

The follow up questionnaire will be administered three months after completion of the Autism ABCs program. It will consist of: 1) The PSC; 2) The APS; 3) The SCS; 4) outcomes of the caregiver-directed goals (generated after each module is presented).

Procedures

Prior to beginning this project, I met with Utah FEAT (Utah Families for Early Autism Treatment), a parent advocacy group that had already expressed a desire to develop such a parent education series. Utah FEAT reviewed the proposal and offered feedback and guidance throughout the project. Topics to be covered in the program were first identified, and then a list

of experts who may be willing to assist in developing the training content was generated. A written summary of the project and requirements was sent to each potential developer, followed by a phone call to answer questions and provide additional information. Developers agreeing to assist in this project were secured.

As the content was being developed, Dr. Carbone and I met to discuss and develop the study design and IRB proposal to evaluate the pilot. This proposal was submitted and approved by the University of Utah IRB. The design will be shared with the developers prior to the presentation of the first pilot.

A flier advertising the upcoming training was also developed. Approval to use agency logos on the flier was obtained and a draft was disseminated to all developers for input and refinement. The flier, once finalized, was sent to all content developers and local providers who offer diagnostic and/or therapeutic services. Although the original intent was to also post the flier on statewide resource web sites, the response was immediately large and such advertisement was not necessary for the initial pilot.

Content for each of the modules was submitted to me in Power Point format. These slides are currently being uniformly formatted. They will be returned to the pilot presenters (comprised of at least one of the module's developers) for their use in the pilot training. Additionally, persons with specific knowledge and expertise have been secured to serve as content reviewers. These people have agreed to review the training in written and/or videotape format and offer feedback and suggestions for improvement.

Discussion

It is our hypothesis and hope that this training will provide important and useful information to families. To be certain, evaluation of the training three months after its presentation will be analyzed. This information, along with feedback from outside reviews will be used to revise and finalize the training content. Documentation of the level of community interest in the training will also be obtained. Last, plans to fund and disseminate this training to families in their local communities across the state will be developed and pursued.

References

Autism and Developmental Disabilities Monitoring Network Surveillance Year 2002 Principal Investigators; Centers for Disease Control and Prevention. Prevalence of autism spectrum disorders: Autism and Developmental Disabilities Monitoring Network, 14 Sites, United States, 2002. *MMWR Surveill Summ.* 2007;56(1):12-28.

Looman WS. Development and testing of the social capital scale for families of children with special health care needs. *Res Nurs Health.* Aug 2006; 29(4):325-36.

McGrew S, Malow BA, Henderson L, Wang L, Song Y, Stone WL. Developmental and behavioral questionnaire for autism spectrum disorders. *Pediatr Neurol.* Aug 2007;37(2):108-116.

Myers SM, Johnson CP. Management of children with autism spectrum disorders. *Pediatrics*. Nov 2007;120(5):1162-1182.

Rhoades,R, Scarpa,A and Salley, B .The importance of physician knowledge of autism spectrum disorder: results of a parent survey. *BMC Pediatr*. Nov 20, 2007;7:37.

Schieve LA, Blumberg SJ, Rice C, Visser SN, Boyle C. The relationship between autism and parenting stress. *Pediatrics*. Feb 2007;119 Suppl 1:S:114-121.