NCFR 74th Annual Conference – November, 2012
Proposed Workshop – Outline

Title: Enhancing Family Life when Autism Spectrum Disorder is Present

Short Abstract:

An estimated 1 in 110 children/youth and their families cope with an Autism Spectrum Disorder (ASD). This workshop aims to update educators and practitioners regarding signs and symptoms of ASDs; referral and diagnostic procedures and tools; theoretical perspectives helpful to understanding manifestations of family stress and coping; research findings; noteworthy treatments and interventions; policy issues; and implications for future research and practice. Opportunities to analyze video footage and case studies, pose questions, and engage in discussion will be provided.

Long Proposal:

Presenters:

Lead Presenter: Dr. Joseph A. Gentry, Ph.D., BCBA-D
Licensed Psychologist
Certified School Psychologist
Board Certified Behavior Analyst – Doctoral
Gentry Pediatric Behavioral Services, PLLC
7600 N. 16th Street, Suite 218
Phoenix, AZ 85020
http://gentrypbs.com/Joseph_Gentry_Ph.D.html
http://gentrypbs.com/Home_Page.html

Presenter 2: Dr. Deborah B. Gentry, Ed.D., CFLE
NCFR Academic Program Review Liaison

Director of Instructional Development
1500 W. Raab Road
Heartland Community College
Normal, Illinois 61761

Professor of Family Science and Associate Dean Emeritus
College of Applied Science & Technology
Illinois State University
Normal, Illinois 61761

Presenter 3: Sarah A. Gentry, M.Ed.
Clinical Diagnostician
Home & School Behavioral Consultant
Gentry Pediatric Behavioral Services, PLLC
7600 N. 16th Street, Suite 218
Phoenix, AZ 85020
http://gentrypbs.com/Sarah_A._Gentry__M.html

I. Intended Audience:

Family professionals (e.g., educators, practitioners, and researchers) in academic, health, legal and policy settings.

II. Aims and Goals of Presenters:

A. Provide update on research findings (along with their limitations and strengths) concerning the incidence of Autism Spectrum Disorders (ASDs) and their impact on family life; best practice interventions and services for individuals with autism and their families; and current and emerging policies.

B. Discuss common signs and symptoms of ASD, as well as referral trends and practices.

C. Discuss effective assessment/diagnostic procedures and tools. Additionally discuss diagnostic terminology.

D. Apply multiple theories (e.g., Double ABCX Model of Stress, Resource Theory, and Systems Theory) while analyzing family dynamics in families where ASD is present (e.g., parent-parent, parent-child, sibling, grandparent-grandchild, and other relationships).

E. Compare and contrast multiple treatment and intervention approaches, strategies, and techniques, especially those that operate from or are compatible with a systems perspective.

III. Intended Outcomes for Participants:

A. Acquire new knowledge about ASDs, their impact on family dynamics, and ways to minimize challenges and better manage related stress.

B. Acquire new knowledge about autism related diagnostics, interventions, and services, as well as policies that can impact them.

C. Acquire basic skills in 1) recognizing signs and symptoms of ASD and related stressors/stress and 2) providing appropriate referrals for services and supports.

IV. Methods Used in Preparing for Workshop:

A. Review of the literature, including two recently published meta-analyses of research studies conducted during two decades, pertaining to families with children who have ASDs and assorted interventions they partake in (Singer, Ethridge, & Aldana, 2007; Meadan, Halle, & Ebata, 2010).

B. Observation and analysis of experiences as specialist and practitioner.

V. Methods for Presenting Workshop

A. Lecture using PowerPoint, though kept to a minimum.
B. Video clip illustrations.
C. Presenter and/or participant conducted analyses of case studies.
D. Participant contribution to discussion and opportunity to ask questions.

VII. Analysis and Preliminary Results:

A. Nature and scope of ASD as a condition affecting children and families.

1. There are three different types of ASDs: Autistic Disorder ("classic" autism), Asperger Syndrome, and Pervasive Developmental Disorder-Not Otherwise Specified ("atypical" autism) (CDC, 2010b).

2. A person with an ASD might not respond to their name by 12 months of age; not point at objects to show interest by 14 months; not play "pretend" games by 18 months; avoid eye contact and want to be alone, have trouble appreciating the feelings of others or expressing their own feelings; have delayed speech and language skills; repeat words and phrases over and over; give unrelated answers to questions; become upset by minor changes; exhibit narrow and excessive interests; flap their hands, rock their body, or spin in circles; and/or have unusual reactions to the way things sound, smell, taste, look, or feel (CDC, 2010b). The manifestation and severity of ASD symptoms varies from person to person.

3. On average, it is estimated that 1 in 110 children in the U. S. has an ASD. ASDs appear to occur in al racial, ethnic, and socioeconomic groups. Nonetheless, on average, ASDs are 4 to 5 times more likely to occur in boys than in girls (CDC, 2010a). The prevalence of autism spectrum disorders (ASD) in school-aged children has significantly increased in the past decades with an estimated 110 children per 10,000 receiving a spectrum diagnosis (Kogan et al., 2009).

4. The Study to Explore Early Development (SEED) is a multi-year study funded by CDC to help identify factors that may put children at risk for autism spectrum disorders (ASDs) and other developmental disabilities. All of the causes

and risk factors associated with ASD are currently unknown. Multiple factors are likely at play, including environmental, biologic, and genetic ones (CDC, 2010b).

5. It is estimated that the lifetime cost to care for an individual with an ASD is $3.2 million (CDC, 2010a).

B. Referral, Diagnosis, and Policy approaches.

1. Research has shown a diagnosis of autism as young as age 3 can be reliable, valid, and stable. While there currently is no cure for ASDs, early intervention treatment and other services can greatly improve a child's development (CDC, 2010a, 2010b). Timely intervention services and supports for family members can evidence similar enhancement of family dynamics and functioning.

2. Evaluation procedures leading to a diagnosis may or may not be at a cost. A child's doctor can make a referral to an ASD specialist (e.g., developmental pediatrician, child neurologist, or child psychologist or psychiatrist). With regard to referrals, one's state public early childhood system can be of assistance as can one's local public school system (CDC, 2010b).

3. Though behavior-rating scales offer valuable input from parents and teacher regarding symptoms, these scales alone are often insufficient in establishing a firm diagnosis. For an ASD evaluation, data will need to be gathered via a developmental interview to determine the age when symptoms were first present. Both unstructured and structured (e.g., Autism Diagnostic Interview – Revised) interviews with parents and teachers can be used (Lord, Rutter, & LeCouteur, 1994). Additionally, the Autism Diagnostic Observation Schedule (ADOS), a semi-structured social assessment (Lord, Rutter, DiLavore, & Rissi, 1999), allows for direct observation of the child's skills and abilities during a number of play activities. Finally, observations of the student during social times of the day will provide valuable information on social skills.

4. A recent recommendation by a committee appointed by the American Psychiatric Association has many advocates and parents worried. The recommendation redefining several levels of autism as a single new category called autism spectrum disorder. New guidelines would require more definitive assessment of a person's overall developmental status, including social communication and other cognitive and motor behaviors. While the goal is more accurate diagnosis and treatment, a possible consequence could be that less severe forms of autism may no longer fall within the newly defined spectrum and, thus, not fit the criteria for eligibility to receive certain services (APA, 2012; Easter Seals, 2012).

C. Understanding Impact of ASD on Families.

1. Parenting a child with ASD is highly stressful and challenging for many parents. Parents of children with ASD consistently report higher levels of stress when compared to parents of typically developing children, parents of children with Down Syndrome, and parents of children with other disabilities (Meadan, Halle, & Ebata, 2010). This stress is reported by many divorcing couples as a factor that contributed to the decision to divorce (Grosso, 2011).

2. Research findings concerning the outcomes for children with a sibling with ASD are inconsistent. However, it does appear that marital stress is associated with compromised sibling relationships (Rivers & Stoneman, 2003).

3. Distress experienced by families that include a child with ASD often reaches higher levels when the child with autism enters into new, age-related developmental stages.

4. When applied to families where a child with ASD is present, the Double ABCX Model of family stress and coping provides useful insights and explanations concerning family problems and solutions (Manning, Wainwright, & Bennett, 2011; Siman-Tov & Kaniel, 2011), as do Systems Theory and Resource Theory.

D. Interventions for Children and Family Members.

1. For children and youth who experience significant levels of anxiety, cognitive behavioral interventions, such as the Coping Cat program (Kendall, 1990), can assist them in developing a plan to manage anxiety (e.g., coping self-talk, relaxation training). Regarding social skills, some children/youth might benefit from groups to develop social cognition (Winner, 2009) or playground interventions to increase positive peer [and perhaps sibling] interactions (Licciardillo, Harchik, & Luiselli, 2008). Interventions that focus on environmental manipulations, including Treatment and Education of Autistic and Communication Handicapped Children (TEACCH; Panerai, Ferrante, & Zingale, 2002) and Positive Behavior Interventions and Supports (PBIS; Bradshaw, Reinke, Brown, Bevans, & Leaf, 2008), can be undertaken to prevent problem behaviors from occurring and increase engagement.

2. Families that avail themselves of multiple and varied resources and supports, both formal and informal, attain better outcomes for all members of the family, including the child with ASD.

VIII. <u>Implications:</u>

A. Need for continued refinement of diagnostic procedures, tools, and terminology.

B. Need for more high quality, accessible, cost effective, and well publicized services: Treatment, family life education, community-school education, support groups, respite care and more.

C. Need for more services and supports in communities with lower SES and minority populations.

D. Need for better insurance coverage.

E. Increases in litigation of autism related disputes suggest mediation services could be helpful.

F. Need for improved, rigorous research, especially longitudinal studies. Other foci for future research include 1) families with multiple children with ASD, 2) positive impacts when ASD is present in a family, and 3) father and sibling dynamics.

IX. References:

A. American Psychiatric Association. (January 20, 2012). News release: *DSM-5* proposed criteria for Autism Spectrum Disorder designed to provide more accurate diagnosis and treatment. Retrieved from http://www.psych.org/MainMenu/Newsroom/NewsReleases/2012-News-Releases/DSM-5-Proposed-Criteria-for-Autism-Spectrum-Disorder-Designed.aspx?FT=.pdf

B. Bradshaw, C. P., Reinke, W. M., Brown, L. D., Bevans, K. B., & Leaf, P. J. (2008). Implementation of school-wide positive behavioral interventions and supports (PBIS) in elementary schools: Observations from a randomized trial. *Education & Treatment of Children, 31*, 1-26.

C. Centers for Disease Control and Prevention (CDC). (May, 2010a). Data and statistics, autism spectrum disorders – NCBDDD. Retrieved from http://www.cdc.gov/ncbddd/autism/data.html

D. Centers for Disease Control and Prevention (CDC). (December, 2010b). Facts about Autism Spectrum Disorders – NCBDDD. Retrieved from http://www.cdc.gov/ncbddd/autism/facts.html

E. Easter Seals. (February 1, 2012). Easter Seals and Autism-Blog Archives. Retrieved from http://autismblog.easterseals.com/advocates-worried-about-changes-to-autism-diagnosis-criteria/

F. Grosso, K. (March 3, 2011). Do couples divorce because of autism? *Psychology Today*. Retrieved from http://www.psychologytoday.com/blog/autism-in-real-life/201103/do-couples-divorce-because-autism?page=2

G. Kendall, P. C. (1990). *Coping Cat workbook*. Ardmore, PA: Workbook Publishing.

H. Kogan, M.D., Blumberg, S. J., Schieve, L. A., Boyle, C. A., Perrin, J. M., Ghandour, R. M., Singh, G. K., Strickland, B. B., Trevathan, E., & van Dyck, P. C. (2009). Prevalence of parent-reported diagnosis of autism spectrum disorder among children in the US, 2007. *Pediatrics, 124,* 1395-1403.

I. Licciardello, C. C., Harchik, A. E., & Luiselli, J. K. (2008). Social skills intervention for children with autism during interactive play at a public elementary school. *Education and Treatment of Children, 31,* 27-37.

J. Lord, C., Rutter, M., DiLavore, P., & Risi, S. (1999). *Autism diagnostic observation schedule – WPS (ADOS-WPS).* Los Angeles, CA: Western Psychological Services.

K. Lord, C., Rutter, M., & LeCouteur, A. (1994). Autism Diagnostic Interview–Revised: A revised version of a diagnostic interview for caregivers of individuals with possible pervasive developmental disorders. *Journal of Autism and Developmental Disorders, 24,* 659–685.

L. Manning, M. M., Wainwright, L., & Bennett, J. (2011). The Double ABCX Model of Adaptation in racially diverse families with a school-age child with autism. *Journal of Autism Developmental Disorder, 41,* 320-331.

M. Meadan, J., Halle, J. W., & Ebata, A. T. (2010). Families with children who have autism spectrum disorders: Stress and support. *Exceptional Children, 77*(1), 7-36.

N. Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders, 33*(4), 383-394.

O. Paneria, S., Ferrante, L., & Zingale, M. (2002). Benefits of the treatment and education of autistic and communication handicapped children (TEACCH) programme as compared with a non-specific approach. *Journal of Intellectual Disability Research, 46,* 318-327.

P. Siman-Tov, A., & Kaniel, S. (2011). Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model. *Journal of Autism Developmental Disorder, 41,* 879-890.

Q. Singer, G. H. S., Ethridge, B. L., & Aldana, S. I. (2007). Primary and secondary effects of parenting and stress management interventions for parents of children with developmental disabilities: A meta-analysis. *Mental Retardation and Developmental Disabilities Research Reviews, 13,* 357-369.

R. Winner, M. G. (2009). Social thinking: A training paradigm for professionals and treatment approach for individuals with social learning/social pragmatic challenges. *Perspectives on Language Learning and Education, 16,* 62-69.