Education Program for Parents of Children Recently Diagnosed with Autism
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Background
Families of children who receive a diagnosis of an autism spectrum disorder (ASD) are faced with profound challenges, and many feel a tremendous burden (Muñiga, Steel, Maccolluch & Nicholls, 2010). Parents of children with ASD experience greater levels of stress than parents of typically developing children and even parents of children with other disabilities and chronic illness (Hassall et al., 2005; Tomarik et al., 2004). In addition, parents of children with pervasive developmental disorders have been found to report a lower quality of life compared to parents of typically developing children (Munguia et al., 2007). Recent studies suggest that providing parents of young children with autism information about the diagnosis and effective treatment practices through parent education programs and support groups can decrease parenting stress (Kain et al., 2009; Tonge et al., 2006) and improve overall quality of life (Shu & Lung, 2005).

The Center for Autism and Related Disabilities at the University at Albany is offering a parent education program funded through a grant from the Office for People with Developmental Disabilities in an effort to reduce the stress of parents during the often overwhelming and confusing time period following the diagnosis of an autism spectrum disorder. The goals of the program are to: 1) increase knowledge about autism, 2) decrease parental stress, and 3) improve family quality of life. In an effort to minimize the amount of time parents wait to access resources and information specific to autism following diagnosis, the program is offered on a continuous schedule.

Method
Participants
Families were recruited to participate in this program through the Center for Autism and Related Disabilities (CARD) at the University at Albany and CapitalCare Developmental-Behavioral Pediatrics. In order to qualify for the program, each child is required to meet the following criteria: 1) have a primary diagnosis of an autism spectrum disorder, 2) have received the diagnosis within the past year, 3) be between the ages of 12 months and 5 years of age, and 4) reside in the Capital District of New York and surrounding counties (9 counties in total). Data is available on seven parents whose children met the above criteria and completed the program.

Measures
Evaluation of the parent education program was conducted using reliable and valid tools. To assess level of parental stress, the Parenting Stress Index - Short Form (PSI-SF; Abidin, 1995) was given to parents. The Family Quality of Life Scale (FQOL; Summers et al., 2005) was used to gauge family life. A test of general knowledge of autism was also administered. Each of these measures was completed by parents prior to and following participation in the education program. In addition, to assess overall parent satisfaction with the education program (social validity), a parent satisfaction survey was administered following completion of the program.

Description of Program
The program is offered at no-cost to families of young children recently diagnosed with ASD in the Capitol Region. The goal of the program is to provide accurate evidence-based information to parents in a timely manner (within 6 months to one year following diagnosis) on a variety of important topics such as how to choose treatment, medical/developmental issues, accessing resources and living with ASD. Five 2-hour sessions are delivered in a group format led by a clinical psychologist from CARD and/or a nurse clinician from CapitalCare Developmental-Behavioral Pediatrics. Program format was selected to assist parents in deciphering information they are accessing from various sources (i.e., pediatrician, autism community, internet, etc.).

Results

Autism Knowledge
Parents were asked to answer ten multiple-choice questions related to the characteristics and treatment of autism spectrum disorders prior to and following the parent education program. Prior to the program, parents answered an average of 72.9% of the questions correctly. Following the program, parents answered 80% of the questions correctly.

Parental Stress
Preliminary data suggests that following the parent education program, parents were reporting less stress overall. Specifically, parent stress scores on the PSI were on average in the high stress range (86th percentile) prior to treatment and fell within normal limits (42nd percentile) following treatment.

Family Quality of Life
Data suggests that parents are reporting improvements in quality of life following the program. Parents rated their family quality of life on a 5-point Likert scale (1=very dissatisfied, 2=dissatisfied, 3= neither satisfied nor dissatisfied, 4= satisfied, 5=very satisfied). Prior to the program, parents reported an average rating of 3.90 and following the program the average rating was 4.25. Data showed positive change in all subscales. The greatest change was reported in the area of emotional well-being, followed by positive change in family interaction and disability-related support.

Satisfaction with Program
Parents reported being highly satisfied with the parent education program. Satisfaction ratings were made following the program on a 5-point scale (5=strongly agree, 1=strongly disagree). On average, parents reported overall satisfaction ratings of 4.86 following the program.

Discussion
The preliminary data on the UAlbany Center for Autism and Related Disability parent education program suggests that overall participants are highly satisfied with the program and following the program they are more knowledgeable about autism and reporting lower levels of stress and improved quality of life. The current evaluation of the program is based on a small number of parents that have completed the series. Data will continue to be collected on parents that complete the program with the hope that the program will continue to benefit families of children recently diagnosed with ASD.