

## **Evaluation of a Sibling Support Group for Families of Children with Autism Spectrum Disorders**

### **Study Purpose and Rationale**

Families of children with autism spectrum disorders (ASDs) face many challenges unique to their situation. Though much of the attention has focused on parents, there is significant literature to suggest that siblings are also impacted. Studies have shown that siblings of children with disabilities experience decreased parental attention, increased responsibilities in terms of child-care and household chores, as well as pressure to achieve.<sup>1-4</sup> The needs of siblings are often not obvious to healthcare professionals or parents, and siblings may perceive they do not require professional attention depending on family environment and dynamics. Given that individuals with disabilities are now living longer, supporting young siblings is crucial as many of them become the major caregiver and advocate in the future for their brother or sister.<sup>5</sup>

The literature regarding the social and emotional impact of sibling relationships in families of autism and other developmental disabilities has been mixed - some siblings have been shown to benefit from their experience, some may not be affected at all and some experience negative outcomes. Bagenholm and Gillberg interviewed three groups of siblings matched for gender, birth-order and socioeconomic status and found that siblings of children with ASDs were more negative in regards to their perception of the sibling relationship compared to siblings of children with mental retardation and siblings with typically developing children.<sup>6</sup> They also reported higher levels of loneliness, problems with peers and conduct, as well as attentional difficulties. Gold reported that although the rates of depression were higher in a group of siblings of autism, social adjustment was similar to groups of siblings of typically developing children.<sup>7</sup> Kaminsky and Dewey found that compared to siblings of children with Down syndrome and normally developing children, siblings of children with ASDs reported less intimacy, less nurturance and less prosocial behavior in their relationships with their sibling.<sup>8</sup> However, they also found that these siblings reported more admiration of their brother or sister with ASD and less quarreling and competition in their relationships.

Despite this variable data, several articles have been published showing that siblings of children with disabilities, including ASDs, benefit from social support groups.<sup>4,9,10,11</sup> Burke and Montgomery reported that the positive aspects identified by children who had participated in a support group included being part of the group, and meeting other children with similar needs.<sup>4</sup> In one study by Lobato et al., siblings of children with chronic illnesses or developmental disabilities reported improvement in sibling knowledge, connectedness and behavioral problems after 6 weeks of 90-minute group sessions immediately after and at 3 months after completion of the program. Smith and Perry created a sibling support group for 26 siblings of children with autism and related disorders and found that siblings had more positive self-concepts and increased knowledge of

autism at the end of the group compared to the beginning. These studies were all limited by the fact that they did not have a control group for comparison.

Williams et al. were able to develop a community-based intervention for siblings and parents of children with chronic illnesses (including autism) and randomize participants between full intervention, partial intervention and a waiting list control group.<sup>12</sup> The full intervention group received structured learning about their siblings' illness, psychosocial sessions, a 5-day residential camp, and two 2-hour booster sessions. The partial treatment group participated only in the camp, and the control group was offered the camp after data collection was complete. Investigators looked at 6 different sibling outcome measures and found that the strongest effect from the full intervention group was seen in sibling knowledge of illness, improvements in sibling mood, and decreases in reported sibling behavior problems. At the 12 month follow-up, they also found that improvements on these outcomes and others (attitudes, social support and self-esteem) were maintained over time. This paper noted that the study participants, however, were not low-income and not minority and further studies in these populations need to be done.

In this study, we propose to initiate a sibling support group in an underserved, urban environment where families have limited access to resources. To our knowledge, there are currently no support groups targeted for siblings of children with ASDs in this community. Our goal is to strengthen relationships between our medical center and local services for families of autism and to provide comprehensive, family-centered care. We will conduct a randomized-controlled trial at multiple sites in the community, and our primary outcome measures will be siblings' knowledge of ASD and siblings' perception of their relationship.

### **Study Design and Statistical Procedures**

**Study Design:** This is a prospective, randomized-controlled, intervention study where we will implement and evaluate the effect of a sibling support group for families of children with ASDs. We will enroll 16 participants between the ages of 7-11 who have a brother or sister with ASD or Pervasive developmental disorder (PDD). We will randomize the participants such that half will take part in a support group and the other half will be placed on a waiting list and offered the support group after data collection is complete. We will attempt to match participants in each group by age and age of their sibling with ASD/PDD. The support group will run as four 90-minute sessions weekly for 1 month. The curriculum will be developed using Sibshops, a model developed by Don Meyer which has been used and referred to in previous studies of sibling support groups<sup>3,5,13</sup>. The sessions will contain activities and discussions that will allow participants to meet other siblings, talk about common challenges and joys and discuss coping skills, and learn more about their siblings' disability.

We will evaluate the program with both qualitative interviews and objective questionnaires. (See attached) Parents and children who enroll in the program will be surveyed prior to the program, 1 week afterwards and 3 months following the completion of the program. Control group subjects will complete

surveys prior to the start of the group, 1 month later and 3 months following the completion of the program. After 3 months, the control group will be offered the support group.

**Statistical Analysis:** Qualitative data will be reviewed and analyzed by research investigators to extrapolate major themes and ideas. An unpaired t-test will be used to compare the mean change in score on the questionnaire (pre vs post, pre vs. post 3 months) between the control and intervention groups. No normative data exists on the questionnaire; thus, the mean and standard deviation will have to be calculated by testing the questionnaire in a small pilot group. To detect an effect equal to 1 standard deviation, and in order to achieve a power of 80% with an alpha-error rate of 0.05, we will need 17 patients in the control and 17 patients in the intervention group. At each site, we plan to enroll 8 participants into each group (for a total of 24 control subjects and 24 intervention subjects) such that we will have a sufficient sample size to obtain statistical significance.

### **Study Procedures**

Potential participants will be identified through recruitment at each site. After interested subjects are enrolled, survey questionnaires will be administered and they will participate in the designed curriculum.

### **Study Drugs or Devices**

N/A.

### **Study Questionnaires**

Children and parents will be asked to fill out a questionnaire prior to beginning the support group sessions, immediately after and 3 months after completion of the group. The survey will involve collection of demographic data, qualitative data and objective measures regarding sibling relationships.

Open-ended, structured interviews will be conducted with the children and parents prior to the start of the program. For the children, the purpose will be to explore and evaluate the children's knowledge with the Sibling Knowledge Interview created by Lobato & Kao.<sup>13</sup> We will also assess their attitude towards their sibling and their understanding and knowledge about the support group. Pre-interviews with caregivers will focus on demographics, their perception of the siblings' experience in the family, concerns about the sibling relationship and their expectations and goals of the sibling support group.

Our objective measure will be the Sibling Perception Questionnaire for both parents and children which has been used in other studies to evaluate the effect of sibling support groups<sup>12-14</sup>. The original version, developed by Sahler & Carpenter, is a 23-item scale with 4 subscales to assess siblings' feelings and attitudes to brothers and sisters with an illness, specifically cancer.<sup>15</sup> The questionnaire has been adapted to apply to general chronic illnesses/disabilities and a parent version has been created and used as well.<sup>13,16</sup> The interpersonal subscale has 9 items and focuses on siblings' interpretations of their interpersonal relationships and interactions with significant others such as family in light of their brother/sister's illness. The intrapersonal subscale contains 7 items, and asks how siblings have been personally affected by their brother/sister's illness. The communication subscale contains 4 items, and

relates to siblings' ability to talk to others about their brother/sister's illness. The fear of disease subscale contains 3 items, which related to siblings' worries about 'catching' their sibling's illness. Each item is rated by respondents using a Likert-type scale from 1 (never) to 5 (always). An additional 3 items created by Lobato et al. will be added to the questionnaire regarding sibling connectedness. The questionnaires will be conducted verbally for the children and written for the parents (with available English and Spanish versions).

Once the group is complete, we will also conduct interviews with siblings that will ask for feedback on the experience of the sibling support group, as well as if and how it has changed their attitude or relationship with their siblings. Similarly, parents will be asked about the impact of the sibling group on the child, perceived advantages and disadvantages of the support group, and the potential change in relationship of the child with their sibling with an ASD.

### **Study Subjects**

Participants will be between the ages of 7-11 who have a sibling diagnosed with ASD/PDD. Siblings will not be excluded based on behavior issues and families may enroll more than 1 sibling to the group. Families will be excluded if parents and children are unable to commit to all sessions.

### **Recruitment**

Subjects will be identified through the Herbert Birch Family Services Early Childhood Center located in Washington Heights, the Ambulatory Care Network (ACN), and the Developmental and Neuropsychiatry Program for Children with Autism and other Developmental Disabilities. We will distribute flyers and advertise in parent newsletters with information regarding the sibling group and available dates at each of these sites. We will also send letters home to parents with a tear off portion so they may self-refer siblings who qualify. Clinical staff will be educated on the study so that they may refer families who meet inclusion criteria.

Families will be asked to commit to 7 sessions – one introductory session to collect the baseline information, 4 sessions of intervention, one session of post-intervention evaluation and feedback and another follow-up in 3 months. Families will be provided with transportation and refreshments for each of the sessions, as well as a gift card at the completion of the program. Consent and assent will be obtained by the parents and children to complete the questionnaires and participate in the group.

### **Confidentiality of Study Data**

A unique study ID number will be used for all subjects. Information will be stored in locked, confidential files. Access to data will be restricted only to investigators and all electronic data will be password protected.

### **Potential Risks**

There are no obvious risks to this study - no specific risks are associated with collecting demographic, quantitative or qualitative data from participants. Children participating in the support group may find

the activities or discussions emotionally disturbing, and clinical staff will be available to support any difficult situations.

### **Potential Benefits**

The goal of the group is to provide a support network for siblings of children with ASDs that will address unmet social and emotional needs. Participants in the group will hopefully enjoy the group, have the chance to meet other peers, and learn more about their sibling's illness. By developing a safe space for siblings to explore their feelings of their siblings and themselves, we hope that the parents and children will see benefit from the group. Additionally, the goal of this study is also to assess the feasibility of having a group in this selected community and if successful, could serve as evidence for health professionals and families to advocate for sibling support groups in the future.

### **Alternatives**

Subjects may choose not to participate in the support group. Enrollment is completely voluntary and subjects will be allowed to decline or remove themselves from the group at any time.

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