

## **A Sibling Support Group for Brothers and Sisters of Children with Autism**

*Tara Smith*

Department of Human Development and Applied Psychology, Ontario Institute for Studies in Education, University of Toronto, Toronto, ON

*Adrienne Perry*

Department of Psychology, York University, Downsview, ON and TRE-ADD Program, Thistletown Regional Centre, Etobicoke, ON

### **Abstract**

*The present study examined the effectiveness of a sibling support group for siblings of children with autism. Participants were 26 siblings of children with autism and related disorders between the ages 6 to 16 who completed the group intervention. Questionnaires examining siblings' self-concepts, their knowledge of autism, and their coping/adjustment with a variety of problems were administered before the first group session (pre-test) and again after the last group session (post-test). Results indicated that the siblings' self-concepts and knowledge of autism improved significantly from the beginning to the end of the sibling support group. These findings suggest that the sibling support group was, in part, successful in meeting the stated goals. Clinical implications are discussed and directions for future research are presented.*

Clinicians and researchers in the field of autism and developmental disabilities (DD) have typically assumed that the family is affected in various ways (mainly negatively) as they face challenges unique to living with a child with DD. This assumption has translated primarily into professionals focusing on particular impact on parents. However, some attention has also been paid to the "healthy" siblings in a family, stemming from the belief that these siblings experience significant stressors such as decreases in parental attention, increases in child-care and household responsibilities, pressures to achieve, and role tension (Hannah & Midlarsky, 1985; Lobato, 1983; McHale & Gamble, 1989; McHale, Simeonsson, & Sloan, 1984; Meyer & Vadasy, 1994; Seligman, 1983). Sibling support groups were developed and implemented by clinicians in an

attempt to address some of the unique psychosocial needs of siblings of children with DD.

Siblings of children with autism, in particular, are believed to confront unique challenges in addition to those described above. These include encountering negative reactions from the public due to the stereotypical, repetitive, and unpredictable behaviour of the child with autism who appears physically normal, as well as having to cope with the skill deficits and difficult behaviours of the child with autism (Morgan, 1988; Roeyers & Mycke, 1995). Moreover, several studies have reported greater emotional and/or behavioural problems in siblings of children with autism in comparison to siblings of children with another disability or no disability (Bagenholm & Gillberg, 1991; Fisman et al., 1996; Gold, 1993; Rodrigue, Geffken, & Morgan, 1993). Consequently, sibling support groups for siblings of children with autism may be particularly needed and valuable.

The sibling support groups reported in the clinical literature share several similarities. Many of the goals of these groups include providing information on disabilities to improve siblings' understanding, discussing problems encountered and adaptive ways of coping, and encouraging siblings to express their feelings about having a brother/sister with a disability. In these groups, group leader(s) typically guide the discussion, activities are structured, a selection of movie clips and books are used to illustrate specific points, and role-playing is used as a way to assist in problem solving (Chinitz, 1981; Howlin & Yates, 1990-1991; Lobato, 1985; Summers, Bridge, & Summers, 1991).

However, there are many differences among the sibling support groups as well. These include group composition, with some studies including a wide range of disabilities (Chinitz, 1981; Lobato, 1985; Lobato & Kao, 2002) and others focusing on siblings of children with one particular disability such as autism (Howlin & Yates, 1990-1991). Age of the siblings is also variable, with some focusing on preschoolers (Lobato, 1985) and some including a wide age range (Chinitz, 1981). There are also differences in group structure and organization, such as the number of sessions, ranging from one day (Howlin & Yates, 1990-1991) to eight sessions (Chinitz, 1981). A more recent study by Lobato and Kao (2002) also included a parent group that ran concurrently with the sibling group, with topics corresponding to those of the sibling group.

Many clinicians and service providers working with children with DD and their families tend to offer such group interventions, assuming that sibling groups may be helpful, and some have described their programs (Ferrari,

1984; Howlin & Yates, 1990-1991; Lobato, 1985; McKeever, 1983; Roeyers & Mycke, 1995; Summers et al., 1991). However, there is little research that has examined the potential benefits of sibling support groups in a more systematic, empirical fashion. Of those studies with published descriptions and evaluations, different methods were used in order to evaluate the benefits of sibling support groups. Chinitz (1981) evaluated a sibling support group qualitatively, by giving anecdotes elicited by the siblings during the groups. Howlin and Yates (1990-1991) examined the potential benefits of a sibling group by having the siblings complete a questionnaire at the beginning and end of the day. The questionnaire included general questions covering various topics, such as knowledge of autism and future concerns. Lobato (1985) used a role-play assessment in order to measure siblings' knowledge of DD, as well as the affective quality (e.g., positive, negative, or neutral) of statements they made about themselves, their parents, or their brother/sister with a disability. Despite the differing methodologies for evaluating sibling support groups, in general, studies reported improvements in siblings' knowledge of disabilities, greater self-worth, and more positive interactions between the sibling and the child with the disability (Dyson, 1998; Evans, Jones, & Mansell, 2001; Lobato, 1985). Nevertheless, in order to evaluate the benefits of sibling support groups consistently across studies, more formal and systematic methods for measuring the various goals becomes a necessity.

The main objective of the current paper is to describe the measures and methods developed, as well as results obtained, in our program evaluation of a series of sibling support groups for siblings of children with autism. It was expected that: (1) siblings would significantly enhance their self-concepts from the beginning to end of the group; (2) they would have significantly more knowledge of autism following the group; and (3) they would report better coping/adjustment following the group.

## **Method**

### **Participants**

Participants came from families in the TRE-ADD (Treatment, Research, and Education for Autism and Developmental Disorders) program at Thistleton Regional Centre, who have a child with autism ( $n=23$ ) or related disorder (e.g. Pervasive Developmental Disorder, Rett Disorder, or Developmental Delay;  $n=8$ ). The participants in the present study include siblings from the groups run at different times over several years. Of the 31

siblings that participated in the sibling support group, 5 did not complete the group intervention. There were no significant differences on demographic variables or dependent measures (pre-test) between the 26 completers and the 5 drop outs. Furthermore, 7 of the 26 completers participated in the group more than once but, in these cases, only the data from their first group were used. These "repeaters" did not differ significantly on demographic variables or dependent measures (pre-test) from those siblings who attended the group only once (both of these analyses used a conservative alpha of .01 to compensate for multiple tests).

Thus, the final sample includes 26 siblings of children with autism or related disorders (14 sisters and 12 brothers) between the ages of 6 years, 7 months and 16 years, 3 months ( $M=10.63$ ,  $SD=2.13$ ). Fourteen of the siblings were older than the child with autism and 12 were younger. Twenty-one siblings were from two-parent families, four were from single-parent families, and one was from a different family constellation. The family's estimated socioeconomic status (SES) was based on staff's knowledge of the parents' occupation and educational level and coded into one of three categories. Ten families fell into the lower SES category (e.g., did not complete high school, have unskilled or manual labour job), 14 in the middle SES category (e.g., finished high school, maybe some college/university, have job in technical, clerical, sales area or skilled trade), and 2 in the upper SES category (e.g. university or professional degree(s), high level executive or professional occupations like lawyer, dentist).

Examination of parent responses on the Child Behavior Checklist (Achenbach, 1991) completed for 25 of the siblings prior to intervention showed that 9 siblings (36%) had borderline to clinically significant Internalizing problem behaviours and 5 (20%) had Externalizing symptoms in the borderline to clinical range. Four of these siblings (16%) had both Internalizing and Externalizing scores in the borderline to clinical range. Thus, it can be assumed that this sample, like others in the literature, is a clinical sample and included some children with some significant emotional and behavioural difficulties.

### **Measures**

*Achenbach Child Behavior Checklist (CBCL; Achenbach, 1991)*. This is a 124-item standardized parent-report questionnaire examining both Internalizing (e.g., depression, anxiety) and Externalizing (e.g., hyperactivity, conduct problems) behaviours for children aged four to eighteen. The Internalizing and Externalizing Problem Behaviour Scale

Scores obtained on the CBCL will be used in the current study. The reliability and validity of the CBCL have been well supported by several studies (Achenbach, 1991).

*Piers-Harris Children's Self-Concept Scale (Piers & Harris, 1969; Piers, 1984).* This is an 80-item self-report, true/false questionnaire measuring how children feel about themselves. This measure contains six specific cluster scores: Behavior, Intellectual/School, Physical Appearance and Attributes, Anxiety, Popularity, and Happiness/Satisfaction and a Total score, which was used in the present study. The Piers-Harris can be used reliably with children by age 8 but caution should be used when interpreting results with younger children (Piers, 1984). Studies that have examined the psychometric properties of the Piers-Harris have found it to be a very reliable and valid measure of self-concept (Piers, 1984).

*Autism Knowledge Measure For Young Children (Perry, 1989).* This is a 20-item measure (available upon request by second author) intended to tap children's basic knowledge of the characteristics and causes of autism (e.g., "Do autistic kids have something wrong in their brain that makes them act that way?"; "Is it right that most autistic kids are girls?"). The questions contain simple language suitable for children. The children respond "yes", "no", or "not sure" to the items. Correct answers are summed to produce a Total score, with higher scores representing greater knowledge of autism. Internal consistency for this measure was computed from the initial sample of siblings ( $n=30$ ) using their pre-test scores. The value for coefficient alpha was .68, indicating fair reliability.

*What It's Like To Have a Brother or Sister With a Developmental Disorder (Coping/Adjustment Scale; Perry, 1989).* This questionnaire was developed as a measure of coping/adjustment, based on the clinical and empirical literature, and designed to tap issues deemed important for psychosocial adjustment specific to the situation of having a sibling with DD (available upon request by second author). It is a 24-item questionnaire with a 4-point, verbally anchored Likert scale, as well as two open-ended items (not used in the present study). This measure consists of six rationally-derived subscales: Competence/Knowledge (e.g., "Are you good at teaching \_\_\_\_\_ to do something new (like to tie his/her shoelaces or order a meal in a restaurant?)"); Chores/Expectations (e.g., "Do you have to "babysit" or help to take care of your autistic brother or sister?"); School/Friends (e.g., "Do kids at school or in your neighbourhood ever tease you because you have a brother/sister like \_\_\_\_\_?"); Anger/Resentment (e.g., "Do you get mad at your parents for always paying attention to \_\_\_\_\_ more than you?");

Mental Health (e.g., "Do you think it is normal to have the feelings you do about \_\_\_\_\_?"); and Future Concerns (e.g., "Do you worry that you might have a child like \_\_\_\_\_ when you grow up?"). Subscales are scored such that higher scores indicate greater difficulties in coping/adjustment. The mean scores for each subscale are summed to produce a Total score representing the siblings' coping/adjustment. Internal consistency was computed for the original sample of siblings ( $n=31$ ) using their pre-test scores on this measure. The value for coefficient alpha on the Total score was .49, indicating poor reliability (or lack of homogeneous factor). It was decided post-hoc that the Anger/Resentment subscale would be used, as it has been suggested that siblings' anger and resentment may be an important factor relating to psychosocial adjustment (McHale & Gamble, 1989; Seligman, 1983) and it was a focus in the sibling group intervention. The value for coefficient alpha was then computed for this 4-item subscale and found to be .61, indicating fair reliability for such a brief scale.

### **Procedure**

An age range was set for each offering of the sibling group to ensure similar ages, interests, and needs in participants. Families with children meeting the age range for a targeted group were informed by letter that a sibling support group would be held at the TRE-ADD program at Thistleton Regional Centre. The total number of families contacted over the years inviting the siblings' participation in the group intervention is not known. For each participating family, a member of the TRE-ADD Research staff met with a parent and the sibling at the family's home within two weeks of the first session of the group (pre-test). Parental consent was obtained for siblings to participate in the sibling support group as well as the research component evaluating its effectiveness. Parent(s) were asked to complete the CBCL while the siblings were concurrently asked to complete the Piers-Harris Children's Self-Concept Scale, the Autism Knowledge Measure, and the questionnaire "What it's Like to Have a Brother or Sister With a Developmental Disorder". For younger siblings and those exhibiting reading difficulties, the questionnaires were read aloud by the research staff member.

The sibling support group met weekly for eight consecutive weeks. The goals of the sibling support group included: increasing knowledge and understanding of autism and related developmental disorders; providing the opportunity for siblings to discuss their feelings in an accepting atmosphere; helping siblings to share ways of coping with difficult situations unique to having a sibling with autism (e.g., through role playing); enhancing siblings'

self-concepts; and encouraging siblings to have fun in a supportive environment. These goals were addressed by focusing on exercises, games, and activities that were fun and promoted group cohesion, providing information sessions on autism and related disorders, and facilitating discussions relating to feelings and attitudes associated with living with a brother or sister who has a developmental disability.

Within two weeks of the last group session (post-test), three measures (i.e., Piers-Harris Children's Self-Concept Scale, Autism Knowledge Measure, and "What it's Like to Have a Brother or Sister With a Developmental Disorder") were re-administered to the siblings in their home or at Thistleton Regional Centre.

## Results and Discussion

To evaluate the hypotheses regarding the sibling support groups, three paired t tests were computed (results are shown in Table 1). First, siblings' self-concept on the Piers-Harris was significantly higher at post-test than at pre-test ( $p < .005$ ). This suggests that, as hypothesized, the siblings significantly improved their overall self-concept from the beginning to the end of the group. This is consistent with Lobato (1985), who found that siblings increased their percentage of positive self-reference statements while simultaneously decreasing negative self-statements. However, two limitations should be noted. One is that it has been found that group means often increase (representing a more positive self-concept) upon retest of this measure (Piers, 1994), even without treatment. The other is that, because there was no control group included in the present study, it cannot be determined whether the positive changes were a result of the specific clinical intervention or other generic factors (such as the novelty and excitement of simply participating in a group designed specifically for them or spending some quality time alone with one of their parents on the drive to and from the group session).

*Table 1. Means and Standard Deviations on the Group Evaluation Measures*

<i>Sibling Outcome</i>	<i>Pre-test</i>		<i>Post-test</i>		<i>t</i>	<i>df</i>	<i>p</i>
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>			
Piers-Harris	54.35	8.56	58.77	8.92	-2.84	25	.005
Knowledge	11.40	3.49	13.20	3.04	-2.45	24	.01
Anger/Resentment	8.00	2.62	7.62	2.32	.95	25	.18

Second, siblings' knowledge on the Knowledge of Autism Measure was significantly higher at the end of the sibling group ( $p < .01$ ). The siblings scored at about chance on this measure prior to the group, indicating that they did not possess a solid understanding of the characteristics and causes of autism, which is consistent with other clinical studies indicating that siblings initially had little knowledge of their brother or sister's disability but became more accurate after participating in a sibling group (Chinitz, 1981; Howlin & Yates, 1990-1991; Lobato, 1985; Lobato & Kao, 2002). Therefore, it appears that the sibling support group in the present study may have been successful in helping siblings understand more about autism, and as a result, their brother or sister's behaviours. Once again, however, it should be noted that there was no control group with which to compare changes. Furthermore, the siblings' mean score was 65% at post-test, suggesting that there remains considerable room for improvement.

Third, contrary to expectation, there was no significant difference between pre- and post- in the siblings' feelings of anger/resentment on the Coping/Adjustment Measure. This may be a direct result of the brevity and limited psychometric properties of the questionnaire used to measure this construct. Another possible explanation for the lack of change on this subscale may be socially desirable responding at pre- but not at post-test. Siblings may have felt that they had to give the "appropriate" response to the anger/resentment questions at pre-test, but after the group, in which feelings of anger/resentment were permitted or encouraged, they may have responded more honestly, and this would mask any actual changes over time in anger/resentment. On the other hand, the sibling group may not have been effective enough to change the reality that some siblings are angry/resentful with their family circumstances.

Post-hoc analyses included an examination of the potential additive effects for those siblings that participated in the group intervention more than once. Given the small sample size ( $n=7$ ), the pre-test scores for each "repeater" were examined by visually comparing their first pre-test score with their second pre-test score. No clear patterns emerged across the seven repeaters.

### **General Discussion**

Although it is difficult to make any conclusive statements on the effectiveness of this sibling support group without a control group, this group of siblings reported greater knowledge of autism and better self-concepts following group participation. Furthermore, qualitative data obtained from a brief evaluation form indicated that they enjoyed their

experiences in the group and wished that it would continue past eight weeks. Several children participated in the program more than once because they enjoyed it. They were given the opportunity to discuss their experiences, express their feelings, problem solve, learn about autism in a supportive environment, and equally important, have fun.

Despite the limitations already discussed, the present study makes some significant contributions to the current research literature. First, the sample size is relatively large, the sample is more homogeneous, and the research design is relatively strong in comparison to other published studies. Moreover, the systematic empirical evaluation of the sibling support group showed that one can provide an important clinical service by increasing siblings' understanding of their brother or sister's disability and helping them feel more positive about themselves. In addition, providing sibling groups can help to identify siblings that may need additional services and provide more long-term clinical support for those exhibiting significant problems (e.g., internalizing and/or externalizing problems, poor self-concepts). In the present sample, about one-quarter of the children were provided with further intervention of some sort.

The present study suggests several exciting and innovative ideas for future research. First, given that a proportion of siblings in this study exhibited clinically elevated CBCL scores at pre-test, it would be important to administer a reliable and valid measure of psychosocial adjustment both before and after the group intervention to determine if the group was successful in improving siblings' overall adjustment. However, it would be necessary to use an instrument that is sensitive to such changes over a short time period. It would also be interesting to examine specific aspects of sibling support groups that may be most beneficial to the participants involved (e.g., number and spacing of sessions, duration). Another area that should be explored in future research is the impact of parent and/or family variables on the success of a sibling support group for children. Finally, an important next step would be to determine the durability of improvement by following the siblings again at a later point. Lobato and Kao (2002) found that the decreases in siblings' Externalizing scores at post-test were maintained 3 months post-treatment. In comparison, the siblings' Internalizing scores 3 months later were similar to pre-treatment scores. Therefore, to most effectively examine the positive effects from participating in a sibling group intervention, a control group needs to be incorporated as a major component of the study so that any changes can be attributed to the intervention itself. Moreover, it is important to use measures which are reliable, valid, sensitive to change, and clinically meaningful, to

ensure that the sibling interventions being implemented are clinically helpful and evidence-based.

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### Authors' Note

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### **Correspondence**

Tara Smith  
Ontario Institute for Studies in Education  
University of Toronto  
HDAP, 9th Floor  
252 Bloor Street West  
Toronto, ON  
M5S 1V6

[tlsmith@oise.utoronto.ca](mailto:tlsmith@oise.utoronto.ca)