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# Family Support and Empowerment: Post Autism Diagnosis Support Group for Parents

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Receiving a diagnosis of an autism spectrum disorder often elicits strong emotional reactions from parents of the diagnosed child. Follow-up services and continued support for these families is a necessary component to help families adapt and meet their and their children's needs. This pilot study measured the effects of a six-session, co-facilitated, support group on the advocacy skills and self-efficacy of parents coping with a child's diagnosis. Statistically significant increases in the average mean scores for the three subscales of the Family Empowerment Scale were found. Implications for practice and research are discussed.

KEYWORDS autism, autism spectrum, ASD, support group, diagnosis, Family Empowerment Scale, parents

#### INTRODUCTION

Receiving an autism spectrum diagnosis is a significant event in the lives of families. Stressful circumstances related to their child's behavior, life

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changes required of adapting to the diagnosis, and difficulty accessing the necessary services and resources to support their family are common experiences of parents after receiving a diagnosis (Boullier, Drake, & Banach, 2008; Guralnick, Hammond, Neville, & Connor, 2008). These experiences point to a need for adequate follow-up services. Unfortunately, follow-up services immediately subsequent to diagnosis are not always available or are not successful in meeting the needs of the family. Finding a more effective means of assisting families after a diagnosis is a necessary step toward improving outcomes.

A careful review of the literature on the reactions of parents who have received a diagnosis of autism for a child and the effects of different types of mitigating factors to reduce stress for parents indicate a need for general support for parents. More specifically, research indicates that having access to a support network and receiving support related to their child had the greatest benefit for parents of children with autism (Guralnick et al., 2008). A postdiagnosis parent support group offers potential to help families adapt to the diagnosis, reduce related stress, and navigate service systems. This article outlines the findings of a pilot study that explores the effects of a 6-week support group for parents who recently received a diagnosis of an autism spectrum disorder (ASD) for their child. A review of the literature found no previous studies that examined the effectiveness of support groups for parents in receipt of a recent diagnosis of autism for their child.

#### LITERATURE REVIEW

#### Reactions of Families

Research has been conducted that examined the feelings and reactions of families after receiving a diagnosis of autism for their children. Much of this research focuses not only on the reactions of families about the diagnosis, and their experience and satisfaction with the professionals and service systems that provided the diagnosis. Fleischmann (2004) reviewed 20 narratives of families who discussed their experiences following a disability diagnosis on the internet. Most of the narratives involved an autism spectrum diagnosis. Parents described receiving the diagnosis as a life-changing experience. The range of feelings included shock, guilt, anger, and relief. In another study, Hutton and Caron (2005) conducted 21 phone interviews with families regarding their experiences of receiving the diagnosis of autism. Regarding reactions experienced by families immediately following the delivery of the diagnosis, the study found that 52% felt relieved, 43% felt grief and loss, 29% felt shock or surprise, and 10% felt self-blame.

In interviews with four families, Midence and O'Neill (1999) found that the families felt relieved after receiving the diagnosis. However, the families also reported not receiving the support they needed afterward. The need for improved follow-up support after a diagnosis was again supported by Boullier et al. (2008). In that study, 10 families were interviewed about their experience of receiving an autism spectrum diagnosis, along with five diagnosticians who were interviewed about their experience of delivering a diagnosis. Families and diagnosticians reported anger, sadness, disbelief, and disagreement but also relief, increased closeness, and understanding. Families identified the need for improved follow-up services postdiagnosis to address their reoccurring feeling of inadequate support. A case study conducted by Drake, Couse, DiNapoli, and Banach (2008) suggested a need to support families in advocating for themselves in schools and other service arenas.

The common feelings of sadness, anger, depression, and disagreement revealed in these studies demonstrate various points in the grief process when families receive a diagnosis (Barnett, Clements, Kaplan-Estrin, & Fialka, 2003). Other common feelings found were relief and affirmation (Mansell & Morris, 2004). Boullier et al. (2008) identified increased closeness and parental understanding following a diagnosis of a developmental disability. These findings showed that some families welcomed receiving a diagnosis, particularly if they considered it as a possibility prior to evaluation.

Regardless of whether a family experiences difficult feelings relative to the diagnosis or anticipates and accepts it, effective follow-up services are sought by families and offer many potential benefits. Such services can facilitate acceptance of the diagnosis. They can provide new techniques to deal with the children's behavior and improve parent advocacy skills in securing needed services. They can encourage parental self-care. Even if a family is ready to accept the diagnosis, time is needed to process the information. Support can help them learn to navigate complex educational, social, and medical systems. Sustained supports are needed to help families to better adapt to the impact of diagnosis over time.

## The Effects of Support

To design more effective interventions for families, an understanding of the different forms and functions of support families seek is necessary. Twoy, Connolly, and Novak (2006) analyzed the responses of 55 parents of children with autism who completed the Family Crisis Orientation Personal Evaluation Scales (F-COPES). The F-COPES includes questions related to the types of support. The results indicate that 68% sought general support from friends and 93% sought information and advice from families with a similar diagnosis. Eighty percent also sought information from professionals. These findings indicate that though general support from friends is important, specific support from families who have had the same experiences or support from professionals with knowledge about disabilities is especially desired.

Guralnick et al. (2008) demonstrated the effects of five forms of support on two types of stress: parent and child-related. Their study analyzed the responses of 55 mothers to the Parenting Stress Inventory and the Inventory of Parenting Experiences, at the initial time of the study and then again 2 years later. *Parent-related stress* referred to stresses affecting the parent's general well-being such as depression or feelings of role restriction and parenting competency. *Child-related stress* was defined as stresses directly linked to their child's particular characteristics such as difficulty adapting to new situations or mood and emotional responses. "Parenting support" was identified by the authors as help and advice specific to their child and caretaking needs. "General support" included general emotional support and time availability. Four distinctions of general support were made based on the source of the support: intimate, friend, extended family, and community.

The findings indicated that by the second evaluation, four types of support had some impact on reducing parent-related stress and child-related stress. The correlation was significant when accounting for all four types of support combined. Community support alone, however, was not correlated with reducing either form of stress to any degree. More notably, the parenting support variable was the only one that demonstrated unique variance on both types of stress at the later measurement. That finding indicates that though having a general support network can benefit parents, receiving parenting support specific to the child and his or her needs is of utmost importance in helping families.

## Support in Groups

Group support can offer parents the knowledge, understanding, and acceptance they seek. In a study by Woodgate, Ateah, and Secco (2008), a common experience described by 14 parents of children with autism was extreme social isolation and lack of understanding from others. This finding suggests that one of the greatest needs for families coping with a diagnosis is finding acceptance and support from others. Little research has been done on outcomes for families and caregivers involved in support groups for autism or other developmental disabilities. Law, King, Stewart, and King (2001) found that parents of a child with a disability reported substantial positive gains from involvement in support groups. The parents reported an increased sense of belonging with peers in the group. They also discussed feeling an increased sense of power in their ability to come together and advocate on behalf of their children, at the community level and within service systems and agencies. The study found that parents in support groups felt increased knowledge and skill in dealing with behavioral issues and other day-to-day concerns. So group support appears to be an effective means for meeting the needs of families, but is there a question of timing in the effectiveness of the support?

Mansell and Morris (2004) found that when a support group facilitated by a family services worker was offered as a postdiagnosis service at a childhood evaluation clinic, parents ranked it the highest in usefulness of all sources of postdiagnosis information available. In another study, Vitsika and Sharpley (1999) attempted to measure support group outcomes more specifically than whether or not participants enjoyed it or found it useful. A pre- and posttest Likert-type scale was administered before and after each session to assess the impact of the program in four areas: self-concept or esteem, self-efficacy, group cohesion, and stress level. Decreased stress and increased self-concept occurred, but group cohesion and self-efficacy did not show lasting changes. The lack of change in self-efficacy suggests that the group participants did not increase their confidence in caring for their child, but the increase in self-concept and decrease in stress show promise for the effectiveness of support groups in helping a parent adapt to a diagnosis of autism. Group members reported value in being understood by others and being able to support others.

Barnett et al. (2003) proposed a support group model for parents of a child with a disability. The model focused on helping parents' through their grief process, in response to their child's diagnosis. The support group offered benefits including feeling a sense of belonging, gaining peer and professional support, and helping parents to process their feelings about the diagnosis. Exploring present and future challenges and finding ways to maintain hope were a part of the discussions. Though the Barnett et al. group design lacks goals specific to building skills in self-advocacy for services, it does recommend providing information about such resources.

## Schools and Support Groups

Schools play an integral role in the lives of children. It might be expected that school-sponsored support groups would be commonly offered to families, given schools' legal responsibility for individualized education (Individuals with Disabilities Education Act [IDEA], 2004). However, there is little evidence of parent support groups sponsored by schools.

In a meta-analysis of program models for young children with autism, Dawson and Osterling (1997) found that programs that were university affiliated had common elements pointing to the need for parent support groups and the involvement of parents in intervention. Beyond university-affiliated programs, more recently community-based parent support groups have provided a forum for feedback about the special education process (Fish, 2006; Spann, Kohler, & Soenksen, 2003). Although the need to involve and support parents of children with ASD has been consistently identified in the literature for over a decade, schools have not taken the lead in doing so. An exception to this was found in a recent study by Kratochwill, McDonald, Levin, Scalia, and Coover (2009), which found that a school-sponsored support group for parents of children in kindergarten throughthird grade with a disability resulted in significantly greater family

adaptability. Although promising, the scant evidence of school leadership in the involvement and support of parents represents a gap in the literature.

The lack of research relative to school-sponsored parent support groups is consistent with the general lack of local resources for families that we have found that prompted a need for and the design of a short-term support group for parents whose children had recently received a diagnosis of ASD. Given the lack of services for families, postdiagnosis of an ASD and the express challenges and needs that families face, supported by the literature, support groups hold potential to fill this void. We set out in the current study to determine whether short-term support groups for parents that incorporate information about ASD, community resources, and self-advocacy are an effective way to meet the needs of families postdiagnosis.

#### RESEARCH METHOD

A pilot study was conducted to determine if support groups could meet the express needs of parents after their child received a diagnosis of an ASD. The model outlined by Barnett et al. (2003) was used to provide a framework for our pilot. However, this model had not been evaluated and lacked the advocacy skill training for parents, which was recommended by Drake et al. (2008). Therefore, the current pilot study involves a partial replication of the group model proposed by Barnett et al. with the addition of advocacy skill training in an effort to study the outcomes for families.

## Support Group Model

A psychoeducational approach was used in the implementation of two 6-week support groups for parents using a modified model proposed by Barnett et al. (2003). The support group was held in the early evening at a local community center. Participation was free of charge to parents and included child care. Resource packets were distributed over the course of the meetings. The groups were facilitated by two advanced graduate students, one from social work and one from early childhood special education, each under the supervision of faculty from their respective disciplines. The interdisciplinary co-facilitation provided parents with access to expert knowledge in two important areas: group dynamics/community resources and educational systems, two areas of their children's lives that will have major changes as a result of the diagnosis.

The support group worked with families on familial adaptation with advocacy skills. In Session 1 ground rules were negotiated; family members introduced themselves and shared their experience of receiving a diagnosis for their child; families were given a copy of First 100 Days Kit: A tool to assist families in getting the critical information they need in the first 100

days after an autism diagnosis (Koegel et al., 2008); a discussion of common reactions to receiving a diagnosis was facilitated; and the poem "Welcome to Holland" (Kingsley, 1987), which captures the reactions to raising a child with a disability, was read and group members were asked to share their thoughts and feelings. In Session 2 families discussed successes and challenges they faced with their child's behavior, discussed their dreams for themselves and their child, and created a collage representing their family. In Session 3 families continued to share skills, techniques, and resources; families helped each other complete a social story for use with their child; and they completed a quadrant activity, which helped parents to identify goals for their child and rank how important they were for their family. Sessions 4 and 5 addressed advocacy skills. In Session 4 the facilitators presented an overview of the Individual Educational Plan (IEP) process; advocacy skills were discussed; and resources to help with negotiating the IEP process were shared. Special education laws were was explained and discussed. The group developed advocacy strategies regarding their children's education that could be used in IEP meetings. Parents shared their experiences, positive and negative, advocating for their children within their schools up to that point.

In Session 5, a panel consisting of experienced parents of children with autism, a successful adult with ASD, and community agency contact personnel discussed resources. The panel shared their knowledge of resources and services available for families and how to access these services through self-advocacy efforts. Suggestions included contacting the local university for assistance or working with area agencies to creatively access funding for programming for their children. The panel also offered networking opportunities and advocacy to the parents through local ongoing support groups, e-mail lists and online groups. Finally, in Session 6 group members were asked to place themselves on a tree representing the adaptation process, facilitators led a discussion of what families could do in the future, and contact sheets with group member information were disseminated.

## **Participants**

Participants were parents whose children had received a recent diagnosis of an ASD within the previous 6 months. They were recruited through community agencies and diagnostic clinics in a suburban area of the Northeast, United States. The total number of support group participants was 14, with 5 in the first group and 9 in the second. Support group participants were given the option to participate in the research. The research study participants totaled 11, with 9 females and 2 males. The first group comprised three females and two males all of whom were White. The second group comprised seven women and two men. One of the women was Jamaican, and the rest of the participants were White. No formal demographic information was taken on

the education and occupations of the participants. However, diversity of experience for the participant was apparent in the discussions. Many participants attended the group after work. Some group members worked in hourly positions, and others held professional positions.

#### Data Collection

To measure the effect of support group participation on the empowerment of parents, the Family Empowerment Scale (FES; Koren, DeChillo, & Friesen, 1992) was used. The FES has good evidence of reliability when used with parents having a child with a disability (Singh & Curtis, 1995). Singh and Curtis (1995) found that the FES was useful in measuring the empowerment components of systems advocacy, knowledge, competence and self-efficacy. The 34-item instrument includes three subscales comprising different levels of empowerment: family, service system, and community/political. Subscale scoring was made up of the sum of the respective item score. The range of scores for the family and service system subscales is from 12 to 60. The range of scores for the community/political subscale is from 10 to 50. The higher the score in each subscale, the greater empowerment reflected. The FES subscales include statements covering issues of parent rights regarding services provided, confidence in parenting abilities, coordination with service providers, assistance to other families in similar situations, knowledge of laws, ability to take action when unhappy with services, and understanding of child's disability. Respondents rate their level of agreement to each statement on a fi5ve-point Likert-type scale with 1 = not true at all, 2 = mostly not true, 3 = somewhat true, 4 = mostly true, and 5 = very true.

Pre- and postsurveys were administered to participants of both 6-week support group for parents of children with a new autism diagnosis. The university Institutional Review Board (IRB) granted approval for this research study. The pretest survey was administered in the beginning of the first week of each session. The posttest was administered at the end of the 6th week of each session. All responses were coded and matched pre- and postsession. The data were analyzed with SPSS (15) to obtain descriptive statistics, along with an examination of the mean for each subscale using paired t tests to determine the degree of change in mean scores from pre- and postsessions.

The group process was further evaluated with a qualitative parent satisfaction survey (see Table 1) administered at the final session. This survey had three Likert-type scale questions pertaining to relevance of group discussions and topics covered. For this survey, respondents rated their level of agreement to each statement on a 4-point Likert-type scale with  $0 = very \ low$  to  $4 = very \ high$ . The Likert-type scale questions were followed by three open-ended questions, seeking parental responses to what was most and least helpful, as well as ideas for topics of future sessions.

**TABLE 1** Support Group Satisfaction Surveys (N = 11)

Survey question	Mean rating/response		
1. Appropriateness of discussion topics	3.77		
2. Helpfulness of panel	3.77		
3. Helpfulness of facilitators	3.44		
4. Most helpful	Hearing the experiences of other parents		
•	Panel of experts on autism spectrum disorder (ASD)		
	Receiving the 100 Day Kit		
5. Least helpful	Number of sessions too short		
6. Additional topics to cover	Discussion of various therapies		
	Additional discussion of school systems		
	Discussion of research findings on ASD		

#### **FINDINGS**

Of the surveys administered, 11 sets of usable data were analyzed for statistical significance. Additionally, qualitative analysis was completed for all group member satisfaction surveys (N = 11). Statistically significant changes were found for each of the subscales from the FES, using a paired sample t test that is reported in Table 2. Given the small sample size, an additional analysis of the data using the Wilcoxon matched pairs test was run. The Wilcoxon statistical analysis found almost the same statistically significant results.

### Family Empowerment

Items in the family empowerment subscale revolve around beliefs and attitudes about parental abilities and confidence. Knowing how to handle problems, feeling that family life was under control, and ability to focus on good things as well as problems are some of the specific items. The mean scores increased significantly (p > .024) from 45.91 to 50.91, indicating that participants felt a greater degree of empowerment in considering themselves in relation to their family at the conclusion of the groups. These means also suggest that by the end of the support group indicating parents left the group with a greater understanding of their child's needs.

**TABLE 2** Comparison of Pre- and Postsubscale Scores of the Family Empowerment Scale (N = 11)

	M (SD)			
Item	Pretest	Posttest	F(df)	Significance
Family Empowerment Service System Empowerment Community/Political Empowerment	45.91(4.93) 46.5 (4.93) 31.3 (6.94)	50.91 (3.72) 54.36 (3.47) 37.18 (4.51)	10 10 10	<i>p</i> < .024 <i>p</i> < .000 <i>p</i> < .006

#### Service System Empowerment

Participants were also found to have a statistically significant (p > .000) increase in empowerment with regard to approaching service systems (M = 46.45 - 54.36). Some of the items included in this subscale described the parent's beliefs about their own knowledge and skills in advocating on behalf of their child and confidence in their own ability to make a difference. This finding indicates that parents felt more competent in working with others to meet the needs of their child.

### Community/Political Levels of Empowerment

Statistically significant change (p > .006) was also found for participants in considering community and political levels of empowerment (M = 31.82 - 37.18). Following participation in the support group, parents believed they could effect change in services for their child. Included in this subscale are items regarding belief in ability to communicate effectively with agency administrators and knowledge of the rights of parents under special education laws.

The satisfaction surveys administered indicated that the respondents found meeting the other parents in the group to be very helpful (see Table 1). Parents also found hearing from an expert panel of professionals and parents whose children had been diagnosed several years earlier to be valuable. Parents suggested that a support group lasting longer than 6 weeks would be beneficial. Further responses indicated interest in more information regarding alternative therapies and research and additional information about school systems/IEP.

#### DISCUSSION

### Implications for Practice

Families whose children have been recently diagnosed with an ASD face significant challenges marked by grieving and uncertainty with the future. The parents who participated in the support groups in the current study gained knowledge and felt empowered to support their child. These data mirror the findings from the support group evaluated by Law et al. (2001). The additional focus on advocacy skills and specific information about approaching the IEP added to the curriculum were successful in these parent support groups in the current study. In one of the three subscales from the FES in which statistical significance was found, knowledge of systems and the ability to impact systems effectively was included. Families with a recent diagnosis of autism benefitted from being in a group in which they were able to discuss the best ways to secure services for their children. Although members of the group were in different stages of the adaptation

process, they welcomed the opportunity to interact with other parents facing similar challenges and the chance to get new information about services and the educational system. Although having advocacy skills may have been implied in the model developed by Barnett et al. (2003), purposefully including such skills was found to be an effective for a postdiagnosis parent support group.

Parents made positive gains in self-efficacy through their participation in the support group. This is evidenced by the significant positive changes in items "belief in an ability to influence services" and "belief they can solve problems when they happen." Although the exact reason for the positive gains made in self-efficacy is not clear, the group members' statements about the value of meeting with and getting support from other parents who had children with autism cannot be underestimated. As noted in the review of the literature, the isolation that parents of children with autism experience can be profound. The time of diagnosis is one of crisis and opportunity. This support group allowed parents to help one another in a time of uncertainty.

This model's reliance on a co-facilitated, interdisciplinary team also appeared to help with facilitation of advocacy skills. Having a social worker with knowledge of group dynamics, paired with an educator with knowledge of school systems, was a powerful combination. The benefit to families of collaborative work among professionals is a more comprehensive program design that utilizes the skills of all professionals (Sandall, Hemmeter, Smith, & McLean, 2005; Blue-Banning et al., 2004). The co-leaders, in their feedback to faculty, valued the expertise of their co-facilitator in the group process. In satisfaction surveys, the group members also commented favorably on the panel of experts which was part of this group model. Since this group was envisioned as a "bridge" to help members become familiar with and connect to community resources, it appears that this intent was accomplished.

Although effectiveness can be attributed to overall knowledge of advocacy and belief in the ability to influence systems, among the topics which showed positive change but may need further examination were the areas pertaining to special education rights and laws, as well as a strong understanding of the diagnoses. Although both of these specific areas were addressed throughout the support group the statistical significance was grouped with many items. The complexity of systems and educational law relative to disability may need to be revisited periodically for families. To affect change for families in the future, greater clarity and information sharing may need to be added to the model. At least one respondent suggested the possibility of doing role plays to anticipate how to manage IEP meetings.

Additionally, strengthening the curriculum to specifically discuss intervention approaches for working with children with autism should be considered. Although the *First 100 Days Kit* (Koegel et al., 2008) that was disseminated to all group members includes information about IEPs and

treatment interventions for children with autism, this finding highlights the need for parents to have more explicit conversations about these issues. As noted in research that explored the reactions of parents to receiving a diagnosis (Boullier et al., 2008; Hutton & Caron, 2005), during the initial period postdiagnosis, families might take in all of the information they receive. However, they may need more specific support to assist them emotionally to sort through and synthesize the information. Further, the 6-week time frame may have been insufficient to give families what they may need during the transition. In fact, group members in the satisfaction surveys indicated that they wished the group met for more than 6 weeks.

Trying to reach a broader base of families is important to future practice. The families who attended the group were self-selected and likely highly motivated to seek out the type of information provided in a support group. Reaching families that are not inclined to participate in a support group is crucial for improved outcomes for the family and child. Finally, the time and schedule of the group might be reconsidered. Using an evening group created potential conflicts with dinner at the start and bedtime for children at the conclusion of each individual session. Some families likely would have preferred a daytime group. Considering groups at different times of the day and with a longer format may improve participation and outcomes for the future.

#### Research Limitations

Clearly, one major limitation of this pilot study is the small sample size. Although statistical significance was found for all three subscales from the FES, it is not possible to generalize from these findings. Because the group members were self-selected and more likely highly motivated to seek out support and services, the significance of findings may also be uncertain. Additionally, the two groups had different sets of facilitators. Although the facilitators coordinated efforts and the curriculum was the same for each group, the service delivery and discussions may have varied, having an impact on the results and what the families took away from the group.

The FES has been found to be useful in examining the degree to which parents feel equipped to advocate for their child. However, it may not adequately measure the degree to which parents are able to secure services. Likewise, the impact of the adaptation and a parent's ability to feel empowered may not be easily measured through this instrument. Portions of the scale may not have been representative of topics addressed in the group. Some of the questions pertained to influencing legislation and systemic changes. These were not areas specifically addressed in the curriculum of this support group. Some areas that were included in the group curriculum such as gaining an understanding of their child's diagnosis were not covered in the instrument.

### Implications for Future Research

Certain respondent characteristics such as gender, age, or child's diagnosis may have an impact on the experiences of caretakers. The researchers did not collect the demographic information needed to analyze responses across such variables. Future research could focus on comparing pre- and postresponses across gender, child's diagnosis, age, time since diagnosis, and cultural differences.

It was difficult to assess the cultural competency of the survey instrument due to the lack of demographic information collected from the respondents. Consideration regarding the instrument and the group curriculum should be taken into account when working with a diverse group. This includes varying cultural approaches and attitudes toward disability. Also, how a person responds to stress, distress, coping mechanisms, behaviors, and attitudes toward seeking and accepting help can all be influenced by an individual's background.

The impact on group effectiveness of the interdisciplinary co-facilitated model is also an area to investigate. Banach and Couse (2007) have found that graduate students from social work and special education benefitted from working together on a follow-up project with families who had received an ASD diagnosis for their child. Research examining the extent of mutual gain from interdisciplinary work within a group context would be useful.

#### **CONCLUSION**

Parents who receive a diagnosis of autism for their child are faced with a plethora of feelings and information through which to sort. In the immediate aftermath of receiving a diagnosis, the encouragement and assistance gained through the mutual aid process of a support group can be invaluable in helping parents to get through a challenging time. In the group model piloted and studied, parents were empowered and helped toward making a healthy adaptation for themselves and their child.

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