
Rachel Zeutenhorst

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Abstract
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Action Research Report Submitted in Partial Fulfillment of the Requirements for the Degree of Master of Education

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Parent Support Groups and Well-Being:

Investigating the Benefits of Parent Support Groups for

Families of Children with Special Needs

by

Rachel Zeutenhorst

B.A. Northwestern College, 2013

Action Research Report
Submitted in Partial Fulfillment
of the Requirements for the
Degree of Master of Education

Department of Education
Dordt College
Sioux Center, Iowa
April 2017
Parent Support Groups and Well-Being:

Investigating the Benefits of Parent Support Groups for

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by

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04/27/17
Date
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Abstract

This qualitative research study seeks to identify if peer support groups for parents with children who have disabilities are beneficial to the parents’ physical and emotional well-being. Previous literature has shown that parents of children with disabilities feel more knowledgeable, accepted, and empowered when they are able to share their successes and struggles with parents who are in similar situations. Furthermore, the literature also shows that when parents are actively involved with their child’s school, other parents, and their community, their children earn higher grades, attend school more often, have better social skills, and are more likely to attend college and graduate schools after graduation. For this study, parents of an existing local support group were interviewed and surveyed to gather information for this study. This action research provides the conclusion that a parental support group can provide long lasting physical and emotional benefits.
According to the researcher’s Parent Support Group Survey conducted in January 2017, 64% of mothers in the M.O.S. T. (Mothers of Special Treasures) support group feel isolated from other people in their community. Furthermore, this survey also indicated that 56% of these mothers worry about their disabled child’s future, and 46% of them feel like they are not doing enough to provide and care for their child. Additionally, other researchers in this study have confirmed that families who have children with disabilities have feelings of unresolved grief, asking themselves questions such as, “Did I contribute in any way to my child’s diagnosis?” “How are we going to support our child’s different needs?” and “What is going to happen to our child when they are an adult?” (Smith, 2014). These feelings of guilt have often led to tension, stress, isolation, and break-ups in families. Moreover, low-income families are more likely to have a child with a disability than a high-income family (Children’s Defense Fund, 2003). Therefore, these families often do not have the time or money to participate in normal family activities. According to the researcher’s Parent Support Group Survey, 46% of mothers have difficulties finding childcare, and 36% indicated that they struggle to balance their careers with their spouse. Due to a combination of these factors, the Journal of Consulting and Clinical Psychology stated that the divorce rate among parents with children who have Attention Deficit Hyperactivity Disorder (ADHD) was twice as high as couples in the general population. In fact, by the time an ADHD child was 8 years old, 22.7 percent of their parents had divorced compared to 12.6 of parents who didn’t have a child with ADHD (Wymbs, Pelham, Melham, Gnagy, Wilson, & Greenhouse, 2008). Additionally, for a family that has an autistic child, the divorce rate can be as high as 75% (Sobsey, 2011).

Problem

When one considers that 64% of mothers who have children with disabilities feel isolated from other families and activities (Parent Support Group Survey, January, 2017) one can assume that vital pieces needed to build support and well-being in a community are missing. In fact, a study from 2014 recently affirmed that peer support was beneficial, and the reason was because of the peers having similar situations or “shared experiences” (Shilling, Bailey, Logan, & Morris 2014). Similarly, the Southwest Educational Development Laboratory (SEDL) noted in their journal A New Wave of Evidence: The Impact of School, Family, and Community Connections on Student Achievement, “When schools, families, and
community groups work together to support learning, children tend to do better in school, stay in school longer, and like school more” (Henderson & Mapp, 2002). Furthermore, the SEDL’s study concluded that when parents are actively involved with their child’s school and other parents, their children earn higher grades or credits, attend school more often, have better social skills, and are more likely to attend college and graduate schools after graduation (Henderson & Mapp, 2002).

It is important that parents and teachers work together in order to achieve the best learning environment for the child. However, even if partnerships and support groups are available to parents, many of them do not have the time, childcare, or resources to attend parent meetings, conferences, or their child’s school activities. It can easily become an economic constraint. Additionally, many parents do not attend school activities, because of the negative memories they have from their own school experiences. They can also become overwhelmed and burdened by possibly hearing the same complaints or negative comments about their child who has disability. What is more, there can also be linguistic and cultural barriers making some parents feel uneducated or inadequate during school meetings (Finders & Lewis, 1994). Finally, many parents do not feel comfortable sharing personal information with a stranger, and in some support groups and school functions, they also often end up comparing another child to their own (Finders & Lewis, 2004). The Individual with Disabilities Education Act states that

Almost 30 years of research and experience has demonstrated that the education of children with disabilities can be made more effective by strengthening the role and responsibility of parents and ensuring that families of such children have meaningful opportunities to participate in the education of their children at school and at home (Individual with Disabilities Education Act [IDEA], 2004).

One of the main goals of a school and a teacher is to train and lead a child in his or her best learning environment. To provide this, there must be a partnership between school and home, and for private Christian schools, the church is included in this partnership as well. Therefore, a school system is not able to uphold this desire if parents do not feel included, valued, or respected. As a result, to make the connection between school and home stronger, one must discover and implement a structure and strategic plan that builds community and support between parents and their chosen school system.
Research Questions

Parenting plays one of the most important roles in a child’s life and makes a large impact in a child’s Christian faith. Proverbs 22:6 states, "Train up a child in the way he should go; even when he is old he will not depart from it" (English Standard Version). Psalm 78:4 also says, “We will not hide them from their children, but tell to the coming generation, the glorious deeds of the Lord, and his might, and the wonders that He has done” (English Standard Version). Therefore, as Christian educators, it is imperative that we work to provide proper support, encouragement, and love to families who face different challenges and struggles as they raise a child with a disability. For this study, the purpose was to measure the benefits of parental support groups for children with disabilities as well as the effects these support groups can have on parents’ well-being. The questions investigated were:

• Are peer support groups for parents with children who have disabilities beneficial, and are the benefits measurable and long lasting?
• What factors are vital in building peer support?

Definition of Terms

In a study or literature review, a variety of terms are brought forth. Some of them may be unfamiliar to the reader. For this study, the following definitions are stated to establish understanding with the reader. Unless noted, all definitions are the author’s.

Support Group: In a support group, the members meet often to provide each other with various types of help and encouragement. Support groups will most likely have members who share a common struggle or bond, and they work together to build community and empowerment with each other.

Disability/Special Needs: A disability can be physical or mental. It has the potential to put limits on a person’s activities, movements, senses, and academics. Most often, a person’s disability is recognized by the law and is most often referred to as a handicap.
Summary

As one measures the benefits of parental support groups and what is needed to make a support group thrive, the desire is that educators become more aware of the need to not only reach out to their students with disabilities but also to these students’ parents. Hebrews 10:24-25 says, “And let us consider how to stir up one another to love and good works, not neglecting to meet together, as is the habit of some, but encouraging one another, and all the more as you see the day drawing near” (English Standard Version). This study will explore the benefits that peer support groups can provide for parents who have children with disabilities.

Literature Review

The Center for Disease Control and Prevention recently stated that about 1 in 6 children between the ages of 3 through 17 have one or more developmental disabilities (2017). A disability can be physical or mental. It has the potential to put limits on a person’s activities, movements, behavior, senses, and academics. Most often, a person’s disability is recognized by the law and is often referred to as a handicap. Furthermore, a disability usually develops during a child’s developmental stages and continues throughout their lifetime. Since developmental disabilities impact day-to-day functioning, they will affect not only the person themselves but also the important people in that person’s life. In order to promote success for the child and their parents, it is hypothesized that providing support groups for parents of children with disabilities can provide a stronger connection between school and home as support groups give parents the opportunity to develop confidence, contentment, and relationships with teachers and peers who have shared experiences.

In their research article, Shilling, Bailey, Morris, and Logan (2014) performed a qualitative study to see if one-to-one support provided benefits and resources to Great Britain families who have children with disabilities. The researchers hypothesized that since parents of disabled children are the experts, they therefore play vital parts in providing family center services to other families who have children with disabilities. The study was carried out using semi-structured interviews and support groups. For 12 months, 12 parents and 23 befrienders (parents of disabled children who were willing to be mentors) participated and met with each other along with 10 professionals in the fields
of social work, health care, and education. The most common disability of the children in the families was autism, and the participants’ length of involvement in a support group ranged from less than six months to five years. In the 45-60 minute interviews, the parent and befriender groups were asked to discuss how peer support met their needs and why they sought out support from other peers in similar situations. Furthermore, participants were also asked to describe how this support was positively or negatively different from other support they had received in the past.

After the study was conducted, the researchers stated that there was little difference in the opinions of the befrienders, parents, and professionals. The researchers’ conclusions and opinions supported the hypothesis that when peers are able to share common experiences and mentor each other, successful peer support groups can be built (Shilling, et al., 2014). The key outcomes from parents when receiving support from befrienders was reduced isolation, emotional stability, and personal growth. The befrienders received good feelings from helping someone else, personal self-worth, mutual support, and more complete training.

However, throughout the study, befrienders often felt emotionally drained and underestimated by the professionals. As a result, this caused anxiety, feelings of inadequacy, and frustration. Overall, the study produced an accurate hypothesis and proved the importance of peer support in communities.

Limitations of this study were potential sampling biases in that participants were selected from a homogenous sample. Another limitation was that there were no cultural factors since all participants were White British citizens. Finally, there was a potential positive bias as the study focused on parents who were willing to give an hour to discuss peer support groups.

Michael Solomon, Nicole Pistrang, and Chris Barker (2001) researched and conducted a more descriptive study of the benefits parents feel from mutual support groups. In this study, researchers looked to examine three questions: “How helpful did the parents find the support groups?” “How did they perceive the social climate of the groups?” and “What were the relationships between helpfulness and the support group’s climate (Solomon et al., 2001)?” Six out of 12 groups in Greater London chose to participate, and the six groups were made up of 56 individuals. This included 52 women and 4 men with
the average age being 39. All support groups were parent run. The research procedure involved parents completing a questionnaire about their support groups, focusing on the aspects of helpfulness, satisfaction, group climate, and group impact. Finally, each group took part in a focus group discussion, giving the parents the opportunity to share more details about their support group experiences. The grounded theory approach was used to analyze the qualitative data received from the support groups.

Using the data, researchers were able to effectively answer their research questions, and the positive results were very similar to Shilling's study. Each aspect of Solomon's research was evaluated using a rating scale. On a scale of 1-9, the helpfulness category's average was 8.1 (SD=1.2), and the satisfaction rating on a scale of 1-4 was 3.6 (SD=0.4) (Solomon, et al., 2001). According to Table 1, the average Group Environment Scores also indicated content parents.

Table 1:  
*Overall Group Environment Scale Scores*

<table>
<thead>
<tr>
<th>Group Environment Scale Scores (rating scale: 1-9)</th>
<th>Mean</th>
<th>Standard Deviation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cohesion</td>
<td>8.3</td>
<td>1.0</td>
</tr>
<tr>
<td>Expressiveness</td>
<td>6.6</td>
<td>1.7</td>
</tr>
<tr>
<td>Task Orientation</td>
<td>7.8</td>
<td>1.3</td>
</tr>
<tr>
<td>Self-Discovery</td>
<td>6.2</td>
<td>1.7</td>
</tr>
</tbody>
</table>

The focus groups had positive results as well. The qualitative data indicated that parents thought support groups were helpful in three ways. The support groups were sociopolitical, interpersonal, and intra-individual. Parents stated that since they have attended the support groups, they have felt more knowledgeable, accepted, empowered, confident, and in control when it came to their son or daughter’s disability. Furthermore, parents were also pleased with the coping resources and strategies that were provided or suggested. Most importantly, parents strongly agreed that they felt a sense of community by being a part of the support group. It provided them a new outlook and mindset about having a disabled child.
Nevertheless, there were three limitations in this study. First, the sample group was made up of mostly mothers and only a few males. Second, only half of the groups that were invited actually agreed to take part in the study. This created a sampling bias, as the researchers don’t know the opinions of the groups that chose not to participate. Finally, a social acceptability bias may have been a limitation as the focus groups’ discussions may not have been entirely honest, since participants may have felt pressure to say certain comments in front of their peers.

An American study also produced similar results to the previous two studies since it focused on the benefits of Parent-to-Parent programs. A Parent-to-Parent program is a self-help program that matches parents who need support with trained, mentor parents. In their article, *A Multi-site Evaluation of Parent to Parent Programs for Parents of Children with Disabilities* (1999), researchers hypothesized that Parent to Parent programs would help members develop more positive strategies in regards to coping, empowerment, obtaining educational services, and accepting their families’ current situation. The study was conducted in the five states of Kansas, New Hampshire, North Carolina, South Carolina, and Vermont. Participants were parents who responded to various advertisements, and in the end, 128 parents were assigned to this qualitative and quantitative study. The quantitative study involved parents being placed in either an intervention group or waiting list group. The waiting list group acted as the control group. The intervention group received phone calls over a two-month period where they gained instruction on communication skills and information on educational services and family groups. Pre-tests were given before the phone calls began, and post-tests were given two months after the first phone call from a mentor parent. The qualitative study involved selecting 24 participants from each state to be interviewed. After the quantitative study, these participants were assigned a mentor parent from the Parent-to-Parent program. After meeting with their mentor parent several times, telephone interviews were conducted with these participants to see if they would rate the Parent-to-Parent program as helpful or unhelpful.

After taking part in the Parent-to-Parent program, parents were surveyed about their improvements in coping strategies, attitude, and ability to address problems. Researchers noted improvements in these measures for all parents in the intervention
group, except for stronger feelings of empowerment (Singer, Marquis, Powers, Blanchard, Divenere, Santelli, Ainbinder, & Sharp, 1999). In regards to the qualitative study, since 89% of parents found the Parent-to-Parent program helpful, the interviews indicated that the program had the potential to be a strong element in helping families who have child with a disability (Singer, et. al., 1999). This is because many participants in the study replied that it was comforting to discuss issues with parents who understand their reality and were able to offer feasible advice. Limitations to this study were that no other measures were used except self-reports from parents, and the study was conducted during a short time period.

Finally, a research article by Erin McCloskey (2010), examined the importance of finding ways to support parents as they interact with a variety of professionals who design programs for their child. Even though parents are the most important advocates for their special needs children, there is often a disconnect, and parents are not always treated as influential resources in their child’s life. Therefore, the purpose of this study was to seek qualitative data about this topic using a case study that focused on the positioning theory. This included examining the relationship between a special needs preschooler’s setting and progress as well as their parent’s experiences in dealing with the medical, educational, and therapeutic conversations that came up when their preschooler qualified for special education. Using this case study, researchers provided strategies that supported parents’ interactions with special education personnel. Since this was a qualitative study, there was no hypothesis. However, the article presented a very clear and concise research question, which is as follows:

The central question that guides this article is: How do parents position themselves and/or become positioned in their interactions with teachers, therapists, doctors, and school district officials around their child’s special education program” (McCloskey 163)?

September 2006-May 2009 was the timeline for this research project. During the 2006-2007 school year, the researcher attended, audio taped, and transcribed all formal and informal meetings at the preschool. The researcher also interviewed the preschooler’s mother separately on many different occasions.
There were three conclusions or challenges the author received from this research article. One is that it is vital that a parent becomes an informed advocate for their child with a disability (McCloskey, 2010). It is important that parents understand their child, the educational system, and the importance of making contacts with other parents, organizations, and support groups. The mother in this case study, Sherry\textsuperscript{1}, stated that she developed a stronger sense of empowerment when she knew she had the encouragement and support of certain professionals. Secondly, there are many low-income families who don’t have the opportunities, funds, and time to be strong advocates. Therefore, this is a challenge for teachers in that they must work with parents in developing and “providing mentor relationships among parents, either through face-to-face interaction or a technological relationship” (McCloskey, 2001). Furthermore, schools can advertise and inform parents of different organizations and support groups in their communities. By providing these resources, they are encouraging and helping parents become vital parts of their child’s program (McCloskey, 2010). The last conclusion one can receive from this article was how important and influential teachers’ interactions are with parents. Teachers must do their best to establish strong partnerships and resources for parents of disabled children (McCloskey, 2010).

Taken together, these four studies show that parent support groups can play a vital role when helping parents who have a child with a disability. Parents who attend support groups not only gain more information about educational services, but they also gain a stronger sense of empowerment, advocacy, and contentment. However, more studies should be conducted. This includes evaluating support groups over a longer span of time to see if parents’ thoughts and opinions change toward their current support group. Furthermore, researchers should explore more ways support groups can reach out to low-income or diverse families. Finally, additional studies should be completed to discover how the partnership between school and home could be strengthened. All of these future challenges and research topics have the potential to develop more reliability and confirmation for families of children with disabilities.

\textsuperscript{1} Name changed for privacy.
Methods

Participants

The participants in this current study consisted of 11 mothers of special needs children from Pella, a rural town in Iowa. All mothers were English speaking, Caucasian women, and they all attend a parent support group called M.O.S.T (Mothers of Special Treasures) that has been meeting once a month since 2012. M.O.S.T has a Facebook page where mothers can share concerns and updates if they can't make it to the monthly meetings. According to leader and author Mrs. Beverly Roozeboom, M.O.S.T seeks to provide safety and comfort for mothers who have children with disabilities.

"I think what draws the moms to MOST is that it’s safe,” said Rozeboom. "We can come as we are, knowing we don’t have to put on a front for this group. [It] is a safe place to open up about our fears for our children, discouragement over a child’s lack of progress, weariness over yet another hospitalization, how to handle the taunts and teases of other children. We can all relate to the stresses and strains we face in our marriages, the challenges of meeting the needs of our other kids, issues with extended families, our concerns for the future, and so forth” (Van Farowe, 2015).

All participants were informed of their rights and all information they provided remained anonymous and confidential. Demographic information regarding the participants is listed in Table 2.

Table 2

<table>
<thead>
<tr>
<th>Category</th>
<th>Number of Participants</th>
</tr>
</thead>
<tbody>
<tr>
<td>Relationship to Child</td>
<td></td>
</tr>
<tr>
<td>Parent</td>
<td>11</td>
</tr>
<tr>
<td>Stepparent</td>
<td></td>
</tr>
<tr>
<td>Grandparent</td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td></td>
</tr>
</tbody>
</table>
### Child's/Children's Disabilities

<table>
<thead>
<tr>
<th>Disorder</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>RAD (Reactive Attachment Disorder)</td>
<td>4</td>
</tr>
<tr>
<td>Immune Disorder</td>
<td>1</td>
</tr>
<tr>
<td>Bi-Polar</td>
<td>2</td>
</tr>
<tr>
<td>Schizophrenia</td>
<td>2</td>
</tr>
<tr>
<td>ADHD (Attention Deficit Disorder)</td>
<td>3</td>
</tr>
<tr>
<td>PTSD (Post Traumatic Stress Disorder)</td>
<td>2</td>
</tr>
<tr>
<td>Depression and Anxiety</td>
<td>3</td>
</tr>
<tr>
<td>ODD (Oppositional Defiant Disorder)</td>
<td>2</td>
</tr>
<tr>
<td>Intellectual Disabilities</td>
<td>2</td>
</tr>
<tr>
<td>Down Syndrome</td>
<td>1</td>
</tr>
<tr>
<td>Polymicrogyria</td>
<td>1</td>
</tr>
<tr>
<td>Bilateral Sensorineural Hearing Loss</td>
<td>1</td>
</tr>
<tr>
<td>Seizure Disorder</td>
<td>1</td>
</tr>
<tr>
<td>Autism Spectrum</td>
<td>1</td>
</tr>
<tr>
<td>OCD (Obsessive Compulsive Disorder)</td>
<td>1</td>
</tr>
</tbody>
</table>

### Total Household Income

<table>
<thead>
<tr>
<th>Income Range</th>
<th>Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than $10,000</td>
<td></td>
</tr>
<tr>
<td>$10,000 to $50,000</td>
<td>1</td>
</tr>
<tr>
<td>$50,000 to $90,000</td>
<td>6</td>
</tr>
<tr>
<td>$90,000 to $130,000</td>
<td>1</td>
</tr>
<tr>
<td>$130,000 or more</td>
<td>3</td>
</tr>
</tbody>
</table>
When asked if there were financial struggles due to having a child with a disability, 45% of participants responded “yes.” Figure 1 indicates the different events that cause financial stress.

Figure 1

*Events that cause Financial Strain*
When the participants were asked if they encountered any difficult issues with their child’s school or school district, 73% of them responded, “yes.” Figure 2 indicates the school events that bring difficulties.

Figure 2

*Events that cause School Difficulties*

Participants were also asked to rate the struggles they face in raising a child with special needs. Participants were provided a statement and were asked to respond to that statement with a “yes,” “no,” “somewhat,” or “not applicable” answer. Figure 3 shows the responses given. Table 3 shows what number correlates with each statement in Figure 3.
Figure 3

*Struggles in Raising a Special Needs Child*

Table 3

<table>
<thead>
<tr>
<th>Number</th>
<th>Statement</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>I feel like I am not doing enough for my child.</td>
</tr>
<tr>
<td>2</td>
<td>At times, my spouse and I have marital strain.</td>
</tr>
<tr>
<td>3</td>
<td>Our family has sibling rivalries.</td>
</tr>
<tr>
<td>4</td>
<td>Our family has difficulties finding childcare.</td>
</tr>
<tr>
<td>5</td>
<td>My spouse and struggle to balance our careers.</td>
</tr>
<tr>
<td>6</td>
<td>I negatively compare my child to his/her peers.</td>
</tr>
<tr>
<td>7</td>
<td>I feel misunderstood by other people.</td>
</tr>
<tr>
<td>8</td>
<td>I feel isolated from other people in the community.</td>
</tr>
<tr>
<td>9</td>
<td>The constant struggle with schools, doctors, insurance companies, etc. is exhausting.</td>
</tr>
<tr>
<td>10</td>
<td>I feel like some people don’t give my child a chance.</td>
</tr>
</tbody>
</table>

Finally, participants were asked to indicate on the survey any peer or professional support they have received for their child or themselves. Figure 4 indicates these different types of supports.
Figure 4

*Types of Support Received*

<table>
<thead>
<tr>
<th>Types of Support</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Autism Center</td>
<td>10%</td>
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<tr>
<td>NAMI</td>
<td>20%</td>
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<tr>
<td>Respite</td>
<td>30%</td>
</tr>
<tr>
<td>Educational Books</td>
<td>40%</td>
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<tr>
<td>IHH through YESS</td>
<td>50%</td>
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<tr>
<td>Church</td>
<td>60%</td>
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<tr>
<td>Therapy</td>
<td>70%</td>
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<tr>
<td>Friends/Mentors</td>
<td>80%</td>
</tr>
<tr>
<td>Family</td>
<td>90%</td>
</tr>
<tr>
<td>Educational Trainings</td>
<td>100%</td>
</tr>
<tr>
<td>Support Groups</td>
<td>100%</td>
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</tbody>
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**Materials**

The materials used in this study included a survey and interview questions. The survey was created on http://www.surveymonkey.com. Using Survey Monkey provided easy access and confidentiality for the participants.

Pre-planned, semi-structured, interview questions were asked to members of M.O.S.T in roundtable format. The questions were focused, yet open-ended, seeking to understand the benefits they are receiving from M.O.S.T, and how these benefits are affecting their daily lives. All interviews were face-to-face and recorded.

**Design**

A qualitative research design was used for this study. Anonymous surveys and a group interview were used as the tools for data collection. The surveys and interview’s purpose was to determine what factors were vital in building peer support, and if the participants’ membership of the same support group provided benefits to the parents’ overall physical and emotional well-being. The survey and interview questions began by asking a number of identifying and open-ended questions. These questions were then used as variables in the data analysis, and the researcher sorted the participants’ answers in the surveys and interview into different themes and categories.
Procedure

A survey, entitled “Parents of Special Treasures,” was given to all participants. This survey sought to identify the demographics of each family as well as determine the type of disabilities present in the children of these families. Furthermore, this survey also asked participants to address what types of helpful or unhelpful support or interventions they have received in the past, the different emotions they have experienced in having a child with special needs, and what barriers have made it difficult for them to receive help. The interview questions were asked to all participants, and helped the researcher discover if the participants’ needs were being met through M.O.S.T and if their daily life has been impacted by regularly attending it.

The survey was administered to all participants through email while the interview questions were asked during one M.O.S.T’s monthly meetings. Attending one of the monthly meetings allowed the researcher to ask any follow-up questions. After the interview questions were asked, the researcher began studying the responses for any themes or similarities. The themes used were words, phrases, or beliefs that were common in the interview and survey results.

Results

Findings

Of the 22 mothers who received the survey, there was a 50% return rate. All of the surveys were completed online.

Research Question One:

The first research question investigated if peer support groups for parents who have children with disabilities were beneficial and if the benefits provided measurable and long-lasting benefits. According to the survey, 91% of participants reported that the help they have received from their support group was useful. When asked during the interview how M.O.S.T has impacted their emotional health, key words of prayer, community, understanding, confidential, and empowered were frequently mentioned. The word understanding referred to how the participants all go through similar experiences in their lives and can offer support by sharing their own advice and stories. One participant
commented by saying, “No one is “wowed” by anyone’s story or situations. We get it, and therefore, can relate to each other.” Furthermore, the word *empowered* references how when participants leave M.O.S.T at the end of the evening, they feel recharged and ready to tackle obstacles that may or may have come their way. “We feel hopeful for our child, our family, and ourselves,” said one participant. *Community* refers to building each participant up. “Before we leave at the end of the meeting, we make sure everyone is/will be okay and has what they need to keep going,” said a participant. Table 4 and the word cloud made on [http://www.tagul.com](http://www.tagul.com) demonstrate more words that were used frequently in the survey and interview results. The larger words on the word cloud indicate words that were stated more often in participant’s answers.

*Figure 5: Tagul Cloud showing the most commonly used words in the interview*
Furthermore, in the interview, participants stated that M.O.S.T helps them gain connections with other organizations, grants, and programs that can help with insurance, school, and healthcare. One participant was quoted as saying, “I am recently new to the area. This is a struggle when having a disabled child, because programs are different in every state. It can make you feel very defeated. It was and still is encouraging to hear at this group places you can still call or shouldn’t call to get support and funding. We don’t leave defeated when we leave this group.” Another participant stated, “You quickly realize when
having a disabled child that no one hands you the information you need to know. You have
to research and search for it. So to come here to M.O.S.T and get the right information is
invaluable.” Finally, a participant commented, “We all just would like one central resource.
However, all of us have or are going through different situations so when we need advice
from another member who went already through a struggle we are currently going
through, it is a blessing to know that they are there.”

On the survey, participants were asked to assess how they feel about their child
and themselves after regularly attending a support group. Participants were asked to read
a statement and choose an option of “yes,” “somewhat,” “no”, or “not applicable.” Figure 6
shows the results of the participants’ answers. Table 5 shows what number correlates with
each statement in Figure 6.

Figure 6
Assessment after attending M.O.S.T
Table 5

*Statements that correlate with the numbers in Figure 6*

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<table>
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<tbody>
<tr>
<td>1</td>
<td>I worry about the future of my child.</td>
</tr>
<tr>
<td>2</td>
<td>I feel hopeful about having a child with a disability.</td>
</tr>
<tr>
<td>3</td>
<td>I am always learning new strategies and information about having an exceptional child.</td>
</tr>
<tr>
<td>4</td>
<td>I know that I have emotional support, prayer, and encouragement from other people in the community.</td>
</tr>
<tr>
<td>5</td>
<td>I feel more emotionally stable and at peace when I am able to share my joys and struggles with others who have shared experiences.</td>
</tr>
<tr>
<td>6</td>
<td>I feel safe sharing confidential information about my child with people in my community.</td>
</tr>
<tr>
<td>7</td>
<td>I have found and have made friendships with other families who have situations similar to mine.</td>
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</table>

**Research Question Two:**

The second research question focused on what factors are vital in building peer support. Participants were given a statement about what they view is most important, somewhat important, or not important in building a support group. 73% of parents stated they would like information on support services available in their community. 91% of families indicated that they would like to build more connections with other families/parents of children with special needs. Figure 7 summarizes the participants’ overall responses. Table 6 shows what number correlates with each statement in Figure 6.
Table 6
Statements that correlate with the numbers in Figure 7

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<tbody>
<tr>
<td>1</td>
<td>I would like support services available in my community.</td>
</tr>
<tr>
<td>2</td>
<td>I would like to attend more educational seminars/training workshops on specific topics (Speech and Language, Child/Youth Mental Health, Sibling Supports, Autism, ADHD, etc.)</td>
</tr>
<tr>
<td>3</td>
<td>I would like access to or information about therapeutic books/toys/equipment for children with special needs.</td>
</tr>
<tr>
<td>4</td>
<td>I would like to build more connections with other families/parents of children with special needs.</td>
</tr>
</tbody>
</table>

The last interview question to participants asked them to address what their deep hope was for this support group and other support groups that may start in the future. Many answers included words already mentioned in Table 4 and Figure 5, but one participant commented, “We know that many mothers of disabled children still feel isolated. Our hope is that we can find more ways to reach out to them. We want to see M.O.S.T continue to grow.” Another participant said, “It is vital that ours and other support groups continue to accent each other’s strengths, leaning on those strengths when they are
our weaknesses.” A third participant replied, “It is important to keep it a trusting and safe environment for everyone. This can be accomplished by providing a relaxing atmosphere that gives mothers the opportunity to laugh.” Finally, other tips or suggestions provided by participants included not affiliating the support group with any church or school so more feel like they can join, scheduling time to bring in professional speakers or pastors, and continually inviting mothers to join the group, especially moms who are young or have just recently moved to the area.

Discussion

Overview of the Study

This study’s purpose was to determine if peer support groups for parents who have children with special needs provided measurable benefits to a parent’s physical and emotional well-being. The survey was used to gather information about each parent’s demographic, their child’s disability, what they look for in or desire in a support group, and how they would assess their emotional health after regularly attending a support group. In addition, the interview for the M.O.S.T. support group sought to determine how the participants’ daily lives, faith walk, and relationship with their child has been impacted by M.O.S.T. Furthermore, the interview also wanted to discover if belonging to M.O.S.T. has strengthened the participants’ ability to advocate for their child, and along with that, how other organizations, schools, and churches can help families who have children with special needs. Finally, the participants’ deep hope for the future of the M.O.S.T support group was also sought during the interview. The researcher used tables, figures, and a world cloud to determine themes within these results.

Summary of Findings

After analyzing the interview, it can be determined that M.O.S.T does affect the participants in positive ways. The participants were able to express well the purpose of M.O.S.T, and the ways it helps strengthen their physical and emotional well-being. Many were able to give strong examples of the ways M.O.S.T has helped them advocate for their child and fulfill their mission as parents of a disabled child. Furthermore, the participants were able to share factors that are vital in building a successful peer support group. This included goals for their own group and groups that may start in the future.
The survey results also indicated that belonging to a support group helps participants see that they have emotional support, prayer, and encouragement from other people in their community. Furthermore, after attending their support group, participants indicated that they feel more emotionally stable at peace when they are able to share their stories with others who have shared experiences. In addition, many participants wrote that because they are in a support group, they have developed close friendships and connections with other families. In fact, one can infer that many of the participants do not feel isolated from other people in their community, because they belong to a support group.

It is still unclear if support groups help prevent parents from negatively comparing their child to their peers or worrying about the future of the child. It was indicated on the survey that the majority of participants find the constant struggle with schools, doctors, and insurance companies to be exhausting, and only 26% felt that they were consistently learning strategies and information about having a disabled child. During the interview, the leader and group mentioned their desire to host more educational speakers, pastors, and organizations. Therefore, it can be inferred that these numbers may change over the course of next year due to M.O.S.T’s goals for the future.

Recommendations

Based on this quantitative research, the researcher would recommend that peer support groups that follow the framework of M.O.S.T. can promote physical and emotional well-being for a member and can be a strong resource for them as they raise a child with special needs. Confidential, understanding, and empathetic were words used the most frequently in the survey and interview, and the words describe well the important ideas that must be present to make a support group thrive. The researcher’s results also indicate that support groups for parents of children with special needs have the potential to help parents build connections as well as gain insight about various programs or organizations that can help their families. The research from the interview and surveys showed that the support group M.O.S.T. has positive effects on the members. Teachers and other school personnel working with special needs students should be mindful of the potential benefits of a support group and make sure parents are informed about this important source of support.
Limitations

Even though the researcher strived to thoroughly analyze the results of this quantitative study, there were some limitations. First, the study was limited by how many people were interviewed and surveyed. Only eleven participants completed the survey and were interviewed, creating a possible sampling bias. Also, the survey and interview were only given to participants in the M.O.S.T. support group, and all these participants lived in the same area. If more support groups from different towns or cities had been surveyed and interviewed, the results may have been more varied. In addition, since the participants in this study were all Caucasian mothers, the study was limited in that it did not include participants of different races and cultures. Finally, the research results may have been more conclusive if fathers of special needs children were also included in the survey and interview process.

Considerations for Future Study

This study focused on the benefits of peer support for parents of children with special needs; however, additional studies could include investigating what schools, churches, and other organizations can do to help parents who have children with special needs. This could be completed in the form of surveys and interviews, seeking to determine what role and impact these places and people could make in parents’ lives.

Another topic of research to measure parents’ well-being could be directed in more of a case study approach. Researchers could collect data about one set of parents who just recently began a support group. After the parents attend the support group for a year, data could be collected again to assess the parents’ emotional and mental health.

Finally, another study could be directed towards the relationship between the parents and their children who have special needs. This could include surveying and interviewing the children to see what impact their parents attending a support group has had on their lives. Possible research questions could investigate if the child’s relationship with their parents changed after their parents regularly attended a support group, or if the child’s ability to advocate for themselves was strengthened due to their parents attending a support group.
References


http://doi.org/10.1037/a0012719
Appendix A

Parent Support Group Survey

1. What is your relationship to your child?
   • Parent
   • Stepparent
   • Grandparent
   • If other, please specify:

2. Please briefly describe your child’s/children’s disabilities?

3. As a parent, have you ever sought any peer or professional support to help your child or yourself? If so, please specify all types: (Ex. family members, church, seminars/workshops, community programs, support groups, etc.)

4. If you received help, was it useful or beneficial? If so, please describe:

5. Can you suggest any ways in which services aimed at helping children and their parents could be more accessible and available to you?

6. Please rank the following choices about what would be important to you in attending a family support group? (1=Very Important, 2=Somewhat Important, 3=Least Important)
   _____ I would like information on support services available in my community.
   _____ I would like to attend more educational seminars/training workshops on specific topics (Speech and Language, Child/Youth Mental Health, Sibling Supports, Autism, ADHD, etc.)
   _____ I would like access to or information about therapeutic books/toys/equipment for children with special needs.
   _____ I would like to build more connections with other families/parents of children with special needs.

8. After assessing the regular support you may or may not receive as well as the struggles and triumphs you face in raising a child with special needs, please rate each category in regards to your current situation and emotions. (3=Yes, 2=Somewhat, 1=No, and N/A=Not Applicable)

   I feel like I am not doing enough for my child. 1 2 3 N/A
   At times, my spouse and I have marital strain. 1 2 3 N/A
   Our family has sibling rivalries. 1 2 3 N/A
   Our family has difficulties finding childcare. 1 2 3 N/A
   My spouse and I struggle to balance our careers and take care of our child. 1 2 3 N/A
I negatively compare my child to his/her peers.  1  2  3  N/A
I feel misunderstood by other people.  1  2  3  N/A
I feel isolated from other people in the community.  1  2  3  N/A
The constant battle with schools, doctors, insurance companies, etc. is exhausting.  1  2  3  N/A
I feel like some people don’t give my child a chance.  1  2  3  N/A
I worry about the future of my child.  1  2  3  N/A
I feel hopeful about having a child with a disability.  1  2  3  N/A
I am always learning new strategies and information about having an exceptional child.  1  2  3  N/A
I know that I have emotional support, prayer, and encouragement from other people in the community.  1  2  3  N/A
I feel more emotionally stable and at peace when I am able to share my triumphs and struggles with others who have shared experiences.  1  2  3  N/A
I feel safe sharing confidential information about my child with people in my community.  1  2  3  N/A
I have found and have made friendships with other families who have situations similar to mine.  1  2  3  N/A

Family Demographic

9. What is your total household income?
   • less than $10,000
   • $10,000 to $50,000
   • $50,000 to $90,000
   • $90,000 to $130,000
   • $130,000 or more

10. Employment Status: Are you currently...?
   • Employed for Wages
   • Self-Employed
   • a Homemaker
   • Retired
   • Out of Work/Unable to Work
   • Other (please specify):

11. What is the highest degree or level of school you have completed?
   • Elementary School to 8th Grade
   • High School Graduate
   • Trade/technical/vocational training
   • Bachelor’s Degree
   • Master’s Degree or higher
Appendix B

Interview Questions for M.O.S.T. Support Group

1. How has your daily life been impacted by M.O.S.T? How has it affected your relationship with your child/children?
2. How has M.O.S.T. impacted your ability to advocate for your child?
3. What should educators and schools continue to do or work to improve as they educate your child?
4. How has your faith walk been impacted by attending M.O.S.T.?
5. What is your deep hope for M.O.S.T.?