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ORIGINAL PAPER

Support Group Value and Design for Parents of Children with Severe or Profound Intellectual and Developmental Disabilities

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Abstract

The purpose of this study was to interview parents of children with severe or profound intellectual and developmental disabilities to determine the perceived value of support groups and identify recommendations for support group design based on their experiences and feedback. Despite varied experiences with support groups, most parents indicated the value of support groups is in providing a place where parents can feel understood and both share and gather information. Parents recommended support groups be targeted for parents of children with similar disabilities and needs, have flexible structures and qualified leaders, and offer a wide variety of content in various formats. Given parental recommendations for support group design varied, summary recommendations addressing a wide range of preferences are provided.

Keywords Support group · Parents · Children with developmental disabilities · Children with intellectual disability

Introduction

Having a child with severe or profound intellectual and developmental disabilities (SPIDD) can result in both positive and negative impacts to the family unit. For example, caring for children with SPIDD can be fulfilling and a source of happiness (Hastings et al. 2005). Conversely, caring for children with SPIDD can be a source of stress, particularly because they generally require full-time attention (Kennedy et al. 2007). The severity of a child's disability is significantly related to parental stress (Jones and Passey 2004) as well as the likelihood that parents will place their child in out-of-home care (Friedman and Kalichman 2014).

The limitations that inherently define SPIDD often require that parents or caregivers make extra efforts to meet the needs of their children. Parents typically have to acquire information about the intellectual and developmental disabilities (IDD), address unique medical needs, and manage complex care for their child (Hartman et al. 1992). Parents may also face emotional challenges related to their child's disability. Often the initial diagnosis is accompanied by feelings of loss as parents adjust expectations for their child and the role they will play in their child's life (Roper and Jackson 2007; Waisbren 1980). Throughout the child's development, parents frequently report feelings of sadness, anger, frustration, guilt, helplessness, and loneliness as they are faced with the ongoing stressors associated with caring for a child with SPIDD (Jackson and Roper 2014; Florian and Krulik 1991).

Approximately one in six children in the United States has been diagnosed with IDD (Boyle et al. 2011), and about 1 in 100 children are so severely affected that they are significantly limited in their ability to care for themselves (Kennedy et al. 2007). IDD are chronic mental and physical impairments that appear before adulthood (thus affecting development), inhibit a person's ability to independently complete everyday activities (e.g., bathing, grooming, dressing, eating), and are lifelong (Centers for Disease Control and Prevention 2015).

Disability severity (assessed as mild, moderate, severe or profound) is determined by the number of domains of functioning that are affected and the degree to which those domains are impaired (Jackson and Roper 2014). These

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domains generally include considerations of the person's ability to engage in self-care and daily life activities, impairments affecting communication or social skills, learning ability, mobility, and degrees of independent living, self-sufficiency and financial management (American Psychiatric Association 2013). A SPIDD is one that impairs most or all domains of functioning.

Although there are a variety of support services for parents and their children with IDD, parents report that receiving social support, specifically in the form of support groups, is particularly beneficial for coping with the stress of meeting a child with IDD's special needs (Diehl et al. 1991). Whereas there is a vast amount of research on the effectiveness of support groups and group treatment (Yalom and Leszcz 2005), there is limited research on how to design support groups for parents of children with IDD, as well as what aspects make these groups beneficial specifically for parents of children with IDD (Shilling et al. 2013; Solomon et al. 2001).

Parents of children with IDD often use social supports as both a means to understand the situation and as a coping resource. Support groups (a type of formal social support) are designed specifically to offer members a means of social support to enhance coping (Nichols and Jenkinson 2006). Participation in support groups reduces member isolation, facilitates sharing information, allows for both giving and receiving emotional support, provides an opportunity for emotional expression and discussion with others, and encourages growth through group member interaction (Nichols and Jenkinson 2006). Interactions that occur within support groups offer members social support to cope with stress and reappraise stressor events (Sloper 1999).

Parents of children with special and complex needs almost universally report support groups to be helpful (Diehl et al. 1991; Mandell and Salzer 2007). However, much of the data on groups for parents of children with disabilities focuses on training and psychoeducation groups rather than support groups (Lam et al. 2016). Furthermore, much of the research on support groups for parents of children with disabilities describes preexisting support groups and their outcomes rather than providing recommendations for support group design (Solomon et al. 2001). Interventionists designing support groups for parents of children with IDD should focus on a number of factors including (a) group structure, (b) group composition, (c) session content, and (d) facilitation.

Group structure generally refers to the frequency and duration of meetings, location in which groups take place, and other logistical considerations (Nichols and Jenkinson 2006). Whereas some studies that evaluated multiple groups for parents of children with disabilities found similar outcomes among all surveyed members despite differences in group structure (Law et al. 2002), results from other studies suggest that closed groups (ones that only periodically accept new members) provided a better opportunity for group members to build trust with one another and become cohesive compared to open groups (Mohr 2004). In addition, compared to groups that had a fixed number of sessions, ongoing groups fostered more of a sense of belonging within the group (King et al. 2000). The literature also indicates a range of meeting frequency for both closed and open parent support groups that included weekly, biweekly, monthly, and bimonthly meetings (Hammarberg et al. 2014; McCabe and McCabe 2013).

Group member composition and the degree to which parents believe they can identify with one another are significant factors in the consideration of group format (Hammarberg et al. 2014). The degree of *sameness* that parents of children with IDD perceive with their fellow group members is an important factor in a group's success and is an area that needs to be explored further (Solomon et al. 2001). Research that compared support groups for parents whose children had similar disabilities and parents whose children had varied disabilities suggests that groups (particularly brief groups) should be composed of parents of children with similar disabilities or the same disability so that parents are better able to relate to one another (McCabe and McCabe 2013). In addition to similarity in disability type and severity, demographic homogeneity has also been shown to be an important factor for group functioning and cohesion for some parents (Hammarberg et al. 2014).

Session content refers to the format and organizing themes of each meeting. Within the literature, some support groups are primarily discussion-based whereas others are multidimensional and offer a combination of session formats such as advocacy work, skills training from professionals, and open discussion among members; some have structured topics for each session whereas others allow for more organic dialog. A mixture of methods (e.g., use of discussion, audiovisuals, modeling, written materials, and homework) is recommended and frequently used (Hammarberg et al. 2014). Some studies suggest that session content should be determined by the members themselves and that the agenda for each meeting be discussed and agreed upon as a group to better meet member needs (King et al. 2000).

The role of the facilitator in a support group for parents of children with disabilities can vary based on the goals or purpose of the group. Research suggests effective facilitators are articulate, organized, and trained in working with groups and families (Hornby 2014). Parent-led support groups (also called peer-to-peer support groups, mutual support groups, or self-help groups) are organized and facilitated by the group members. Parent-led support groups for parents of children with disabilities provide members with emotional support, community, a sense of belonging, friendship, and a platform for advocacy and empowerment (Shilling et al.

2013). Parents of children with disabilities who participate in parent-led support groups report that the groups are a place for them to share emotions, learn from related experiences of other parents, and gain practical information to navigate institutional barriers and find external resources (Law et al. 2002). Parents of children with disabilities who participate in parent-led support groups also report increased self-esteem and appraise themselves and their family situations more positively than parents who do not (Solomon et al. 2001).

Professionally facilitated support groups are led by professionals such as psychotherapists. Professionally led groups have similar benefits to those found in parent-led support groups (Canary 2008). Although the research on the degree to which parents want professionals involved in support groups is mixed, parents tend to see professionally facilitated groups as an effective means to increase social support and learn skills to help manage the stresses associated with having a child with IDD (Lindo et al. 2016). The use of co-leaders can be valuable in working with parents of children with disabilities, particularly when co-leaders include a mental health professional (e.g., social worker, therapist, or clinical psychologist) and a subject matter expert (e.g., medical professional, occupational therapist, or special education teacher; Fine and Johnson 1983).

Although research suggests support groups can be beneficial for parents of children with SPIDD, little known about the value those parents ascribe to support groups, what they would like from a support group, and how they would like a support group to operate. The purpose of the present study was to develop recommendations for effectively designing and facilitating support groups for parents of children with SPIDD based on parents' needs and preferences. We employed qualitative content analysis, which is a method of inquiry used to derive meaning from a specific group or culture about their own experiences (Graneheim and Lundman 2004) that is commonly used by helping professionals to gather input for developing intervention programs (Downe-Wamboldt 1992). Accordingly, the results of the present study provide guidance for the design of future support groups as an intervention for parents of children with SPIDD by answering the following research questions:

1. How valuable do parents of children with SPIDD perceive support groups to be?
2. What do parents of children with SPIDD recommend in terms of support group design (e.g., frequency of meetings, duration of participation, number of members)?
    (a) What aspects of support groups do parents believe would be beneficial?
    (b) What aspects of support groups do parents believe would not be beneficial?

Method

Participants

Participants were parents of children with SPIDD who had made the decision to place their children in out-of-home care. Participants were part of a more extensive study on placing a child with SPIDD in out-of-home care (Jackson and Roper 2014; Roper and Jackson 2007) in which they were also interviewed regarding support group value and design. A total of 34 participants (15 mixed-gender married couples, 3 individual mothers, and 1 individual father) were selected using theoretical sampling to ensure sample consistency and data saturation (Creswell 2013). Participants met the following inclusion criteria: (a) were the parents of one or more children with a SPIDD based on a state division ability level assessment system (e.g., self-care, language, intelligence quotient, mobility, capacity for independent living), (b) had voluntarily placed at least one child with SPIDD in out-of-home care when the child was between the ages of 2 and 30 years old, (c) were currently married when their child was placed, (d) had placed the child with SPIDD a year or more previous to participating in the study. Previous support group attendance was not required for participation in the study.

A pool of potential participants residing in urban areas in Utah was identified by state and private agencies, and subsequently recruited by the first author. The sampling frame consisted of 75 families, of which 52 were successfully contacted. Of the 52 contacted families, 11 were not interested in participating after the study was explained, 20 did not meet the selection criteria, and 2 met the selection criteria and expressed desire to participate, but could not participate due to extenuating circumstances. A total of 21 families met the selection criteria, and agreed to participate in the study, and were interviewed; two of the interviews were deemed unusable due to a large amount of missing data, leaving a total of 19 usable interviews with 34 participants. Participants did not receive remuneration.

Because parents were recruited based on placement of a child with SPIDD in out-of-home care as opposed to support group attendance, the sample consisted of parents who had attended support groups, as well as parents who had not. About half (56%) of the parents had attended at least one support group (24% attended regularly), about a third (32%) had never attended, and attendance could not be determined for 12% of the sample. As a result, more varied beliefs, experiences, and recommendations regarding support groups were likely provided than would have been if the sample had either consisted exclusively of parents who had attended support groups or of parents who had not. Parents in the sample who had attended support groups typically had done so prior to placing their child with SPIDD in out-of-home care.

The majority of participants were White (97%), Latter-Day Saints (Mormon; 85%), and had four or more children (68%). The average age of the fathers (n = 16) was 50.8 (SD = 9.2) and the average age of the mothers (n = 18) was 49.1 (SD = 10.9). Most parents had some education beyond high school (73%); all of the fathers worked full-time and 26% of the mothers worked full-time, with 16% working part-time and 58% identifying as stay-at-home mothers. The inflation-adjusted annual household income based on the Bureau of Labor Statistics inflation estimation (2017) was \$30,000–\$50,000 for 26% of the sample, \$50,000–\$70,000 for 32% of the sample, \$70,000–\$90,000 for 32% of the sample, and over \$90,000 for 11% of the sample.

In terms of the participants' children with SPIDD, 32% had severe disabilities and 68% had profound disabilities. Based on parent report, all the children had multiple disabilities: 100% had an intellectual disability, 90% had developmental delays, 79% had a communication disorder, 63% had behavioral disorders, 53% had a seizure disorder, 26% had an orthopedic impairment, and 21% had a visual impairment. In terms of specific diagnoses, 53% had autism spectrum disorder, 11% had cerebral palsy, and 5% had Down syndrome. With regard to gender, 58% of the children were male and 42% were female. The average age of the children was 24.1 (SD = 11.0) and the average number of years since placement was 13.4 (SD = 10.4). In terms of initial placement setting, 42% were placed in group homes, 37% were placed in residential care centers, and 21% were placed in professional parenting care (i.e., similar to specialized foster care in which the natural parents maintain custody and the child primarily resides in the home of paid trained adults).

Interview Questions

A set of semi-structured interview questions was developed to gather perspectives about support groups based on the existing literature (Hill et al. 1997). The interview questions were reviewed and revised by content area experts unaffiliated with the study (i.e., a professor of special education, a director of a state agency for people with disabilities, a director of a community advocacy group for people with disabilities, and a professor of family therapy). The following questions are representative of the semi-structured interview questions participants were asked about parental support groups: *Have you ever thought about attending a support group for parents in your situation? Did you attend a support group before, during, or after you made your decision to place your child? Why did you (not) attend? What was your experience like? How helpful or valuable do you think attending a parent support group has been or would be for you?* In addition, participants were asked to describe what the ideal support group would look like for them, including various design aspects (e.g., structure, format, frequency, duration, issues addressed, member recruitment).

Procedure

Each participant provided written informed consent prior to data collection. The first author conducted 19 usable interviews; the 15 couples were interviewed conjointly and the 4 individuals were interviewed independently. Most participants requested to be interviewed in their homes; one interview was conducted at a participant's business office and another interview was conducted at a local community center. After the interview, participants completed written demographic questionnaires. The interviews were transcribed verbatim by trained undergraduate students and research team associates; transcriptions were subsequently verified by the first author who compared the transcriptions with the interview audio recordings and corrected discrepancies.

Data Analysis

The first and second author used qualitative content analysis to code the data and identify themes, meanings and core ideas (Drisko and Maschi 2015). The first step was to become immersed in the data by reading the transcripts in their entirety to get a sense of the whole (Creswell 2013). Open coding generated general categories that were organized and reconstructed to create a coherent set of recommendations for support groups (Drisko and Maschi 2015). Although participants were not specifically asked about the type of facilitation (parent-led or professionally-led), this was coded when it was discernible based on content of the transcripts. We also conducted several matrix analyses (the process of comparing thematic categories across different groups or variables, such as participant characteristics; Tankard 1994) to compare results across participants who had participated in support groups with those who had not; the only meaningful matrix analysis results were for the thematic categories related to assessment of value (see Supplemental Table 1, 2).

We used credibility, transferability, and confirmability techniques during data analysis to establish trustworthiness of the results (Creswell 2013). To establish *credibility*—the degree to which the results are accurate and reflect reality (Shenton 2004)—the first and second author spent time in prolonged engagement with the data (Lincoln and Guba 1985). Frequent meetings were scheduled between the first and second author to facilitate the data analysis process. The third author served as an internal auditor given her expertise in IDD (Shenton 2004). In addition, thick and rich descriptions from the transcripts were included in the results for readers to assess the credibility of the results (Creswell 2013); participant quote selection was monitored to insure that the voices of some participants were not overrepresented compared to the voices of other participants. We addressed *transferability*—the degree to which study findings can be applied to other contexts or situations (Shenton 2004)—by providing readers with information about the data, including research design, participant demographic information, recruitment strategies, and general context of data collection. We invited three parents of children with IDD in leadership roles at a parent-gestated community organization that provides education and support groups for families of people with autism living in a major East Coast metropolitan area to review the anonymized study results; all three invited parents were unaffiliated with the study. One of the three parents who had 5 years of relevant support group experience reviewed the anonymized study results, provided feedback, and overall endorsed the results and recommendations. We addressed *confirmability*—the degree to which the data objectively support the results—through an internal audit by the fourth author and an external audit by another researcher unaffiliated with the study.

Results

Interview analysis yielded results in two key areas: (a) the perceived value of support group participation, including what added or detracted value; and (b) group design recommendations. Several themes and categories were parallel opposites of one another in both key areas. There was some thematic overlap between the perceived value of parent support groups and the recommendations for parent support group design (e.g., aspects parents believed contributed to the value of support groups were often related to what parents wanted in a support group).

Assessment of Value

Most of the 34 parents (64%) indicated that support groups offered some level of value and were beneficial, even if in some cases they had mixed evaluations. Specifically, almost half (47%) of parents exclusively cited beneficial aspects of support groups, 18% had a mixed evaluation (citing both helpful and unhelpful aspects), 29% did not perceive support groups as valuable, and an assessment of value could not be discerned in 6% of the sample. Of the parents who perceived support groups as beneficial, 62% had attended at least one support group meeting and 25% had not; all parents who indicated mixed perceptions about the value of support groups had attended at least one support group meeting. Of the parents who did not perceive support groups as valuable, 30% had attended at least one support group meeting and 70% had never attended. The subsequent percentages provided in parentheses indicate the response frequency for the respective theme or category at the case (interview) level rather than the participant level to not overrepresent the experiences of the participants who were interviewed conjointly as couples over those of participants who were interviewed individually.

Reasons Support Groups Were Perceived as Valuable

Feeling Understood

Most parents (63%) referenced the ways in which support groups provide an opportunity to be with other parents who have a shared experience and understand what it means to have a child with SPIDD. As one mother shared, “Sometimes all people want for [*sic*] is somebody to listen to them, and not try and fix it, not give them advice, not give them answers, but just somebody who listens and says, ‘You know what? I understand.’” In another interview, a father shared the following: “People could share the traumatic experiences that you go through. Until you have an autistic or handicapped child, people that have ‘normal children’ just don’t understand.”

Helping Others

Some parents (32%) indicated that participating in support groups was an opportunity to help others. As one mother stated: “It’s somewhat rewarding to me to be able to reassure them that they’ll survive it and that there are blessings to look forward to, and that kind of thing.”

Positive Experience

Several parents (26%) felt better (or imagined they would feel better) as a result of attending a support group. A number of parents discussed that one of the primary mechanisms that made participating in a support group a positive experience—which included feeling reassured, relieved, and encouraged—was through sharing their emotions with other parents in the group. As one mother said, “We could laugh together instead of cry. I mean, we did both, but it was wonderful.”

Creating Connections

Some parents (21%) addressed the value that support groups have by providing an opportunity to connect to other parents of children with disabilities and build friendships together. One father commented, “I think getting groups together would be helpful to share how you’re dealing with this issue and that issue, and you could develop some relationships.

Like this one couple, they became very fond friends of ours for several years."

Taking Action

Another value of going to a support group for some parents (5%) was feeling like they were taking action and doing something to better themselves and their family situation. One mother described, "It makes you feel like you're doing something about it, instead of just sitting around and having it rain on you. At least you're putting on galoshes or putting up an umbrella."

Reasons Support Groups Were Not Perceived as Valuable

Poor Fit

One of the most common reasons support groups did not fit the needs of the parents (cited in 32% of interviews) was due to the rarity of their child's disabilities or because their child had more severe disabilities than the children of other parents in the group. One mother said, "I've realized I'm not going to find anybody like our child with special needs—he's one of a kind… So, I don't know how beneficial a support group would have been to me." Several parents also discussed the inability to find other parents with a shared experience, and one father said, "You go to these groups to feel like you're not alone, and we'd go to these groups and feel like we were alone again because we had not only two kids with disabilities, but neither one really fit either group."

Does Not Help

Several parents (32%) stated that participating in a support group neither helped their situation nor addressed their feelings about raising a child with SPIDD. Parents shared that participating in support groups did not change things for them and that they did not find talking to other parents to be an effective coping mechanism. As one mother expressed, "It just hasn't gotten us anywhere." Similar sentiments that support groups are more about feeling bad, or searching for pity, were echoed in several interviews. Another mother shared that she sees support groups as "nothing but a bunch of whining and complaining."

Comparison to Others

Some parents (32%) found they compared themselves to other parents. One mother described her experience as a "crying match" with each support group member trying to outdo the other. One father said, "I'm not really comfortable honestly… in a setting where you can compare notes. I'm not terribly interested in your notes, and suspect you wouldn't be in mine." Another mother described that she felt "ostracized" and judged by the group because she had placed her child with SPIDD in out-of-home care. As a father further explained, the other parents "made us feel guilty for... thinking about placing our child with disabilities… There was [*sic*] a lot of kids that were worse off than our child, and their parents were still watching them, you know what I mean?" Most parents described that these types of comparisons often resulted in feelings of guilt, self-judgement, or frustration.

Negative Experience

Several parents (26%) referenced feeling, or expecting to feel, undesirable emotions (e.g., depressed, frustrated) during support group meetings due to the inherent nature of topics. A mother described her husband's first support group meeting: "He just got out of there and said… 'That was the most degrading, demoralizing, depressing hour and a half I have ever spent in my life, and I am never going back.' And he didn't." Parents also shared that support groups were difficult emotionally because it was uncomfortable to be around others who may be struggling. One set of parents shared:

> Mother: Being with other parents should be a support; but in a way, it just makes it all the more hurtful because you just feel so sorry for them and what's going on in their life.
> Father: And you know you're helpless to help them.
> Mother: Yeah, it's just tough. You just don't want to go through it—emotionally you just can't stand that pain and what they're going through—I feel so sorry for them.

Support from Other Sources

Some parents (16%) believed that support groups were unnecessary because they either did not need support or found support from other sources. One father said, "I've never felt the need to go to a support group; I've been able to deal with this okay." Several parents also discussed that because they felt sufficient support from family and friends they did not need additional social support. For example, one father questioned, "What support do we need if all the people to whom we are emotionally close support us? We don't need a support group."

Support Group Design

Analysis generated support group design recommendation themes and categories for developing an ideal support group. The recommendations were based on the collective input of all participants, as most of the interviews did not contain data on each of the themes. The following support group design themes emerged: structure, composition, meeting content, leadership, and member recruitment.

Most parents (95%) preferred meeting one to two times per month. One set of parents suggested the meeting frequency be set with consideration for logistical constraints for those who would like to attend: “Maybe have [meetings] two times a month, so that those that couldn’t come to the first one could make it to the second one.” Parents expressed concern that meeting too frequently would either become repetitive or burdensome (e.g., childcare, other commitments), but that meeting too infrequently would not meet parent needs. Parents suggested a one hour to one-and-a-half-hour meeting. As one mother stated: “We always hated those meetings that went on for hours because you knew your kid was home raising hell, and you were sitting there.”

In discussing the number of sessions parents might attend, some participants (32%) indicated that the duration would vary based on needs of the parent. As one father stated: “Some of that time would be for you personally, but you may also feel that you should stay with the group for someone else too, so I don’t think you can really predict a time.” In terms of group type, there were preferences for open meetings and closed meetings. Parents who preferred support groups to be open said it would allow new members to join groups that are “already formed and going” and other members to leave at any time. One father summed up the argument for groups to be closed by saying:

> I don’t think it would be fair to establish a group and then have one of you leave and have a new one come in. You’d have to kind of start over… [The same participants] would have to go through it together. And then when they felt like it was no longer beneficial, then they have to disband it.

Recommendations around the accessibility of support group meetings centered on meeting time and location. Some parents described attending meetings as difficult because of their schedules. One father noted, “A lot of times meetings would be scheduled when I was out working,” and suggested that support groups “try to work around so that everybody had a time that would be most beneficial.” In one interview, parents described that the location was difficult to access and it would have been helpful to have multiple groups set up in various geographic locations to minimize the “long ways drive back and forth.”

A number of parents (42%) recommended concurrent services be offered either in addition to, or as a part of, support groups. Parents suggested that groups be used to connect with other parents of children with IDD for one-to-one mentoring that could occur outside of the group setting: “If they could have someone’s name to be kind of a buddy that you could call up and say, ‘Oh, I don’t know if I did the right thing.’ And they could say, ‘Well, yes you have because already this and this,’ you know.” Parents also addressed the concern that group attendance was difficult because of a lack of childcare for their child with SPIDD, indicating a need for concurrent childcare services. For example, only one parent was able to attend group at a time if the other parent needed to remain home to watch their child with SPIDD. Parents also suggested concurrent support groups and workshops for their other children.

Composition

Most of the references to group size were descriptive of what parents who attended support groups had experienced rather than a preference or recommendation. Parents’ experiences included attending meetings with fewer than 10 members, 11 to 20 members, and more than 20 members. The most common recommendation (32%) was that groups be composed of ten or fewer members. One father explained:

> It has to be a relatively intimate group to really have some benefit. You have to establish a relationship, you have to feel comfortable sharing with someone else your story… and that’s tough to do unless you have some respect or feelings for others in that group.

Parents discussed the importance of sharing characteristics with other parents in the group. Feeling understood was an often related theme as parents discussed the extent to which they could relate to other parents. The characteristics they discussed fell into four subcategories: the child’s type of disability, disability severity, age and stage of development, and placements status.

A few parents (16%) suggested that support group members’ children did not necessarily have to have the same disability because the emotional experience of raising a child with disabilities, regardless of what those disabilities are, would be similar. As one mother said, “It was helpful to… find out how other moms felt. Even though they did not have autistic kids, they all had special needs kids… We all had a lot of the same feelings and a lot of the same frustrations.” However, several parents (37%) expressed a preference for groups to be composed of parents of children with similar disabilities. Parents often described the frustration of not being able to relate to other parents when the children had varied disabilities. For example, one mother said:

> I would ask questions: “Well, does your kid burn things in the oven and do they tear their clothes all in holes?” And they’d just kind of looked at me like “No.” And I thought, “Well…” I guess I was wanting somebody who was going through the same crap I was.

Several parents also described being frustrated because the information (e.g., medical information, behavioral advice) discussed by other members or, in some cases, healthcare professionals, did not apply to their child's type of disability. As one mother explained, "Every child has such a different disability. What we're faced with is that we want to know something about our daughter's…tendons, but that wouldn't work for someone who has autism—they don't care."

Similar to concerns about disability type, some parents (26%) described that they wanted to be in a support group with only parents whose children had as severe of a disability as their own. Parents either described how meaningful it was to create connections with parents who shared similar struggles, or they described frustration with not being understood when they were in a support group with parents of children with comparatively less severe disabilities. As one mother described, "If you have some little kid that's just got a little whiff of autism, how can they really relate to what it's really like? [It would help to] separate it by level or problem." Another mother explained that although it was frustrating to be with parents of children with less severe disabilities, "To know that there are worse kids out there… would have helped me."

Several parents referred to age or developmental stage as an important group membership characteristic to consider. Some parents (21%) discussed that they would have liked to have been in a group with children in different developmental stages so that they could learn from others who had older children and offer support to parents who had younger children. One mother shared, "We were getting advice from people that had been through it, so that was nice. And then…[later], we were giving the advice because we had been through it." Parents discussed that they would like to have experienced parents with older children in the group, as being the most experienced parents was frustrating when relevant topics were discussed "after it was too late" for the information to be helpful to them. Conversely, one set of parents found it was actually overwhelming to be with more experienced parents who had older children: "We had a brand new baby and my husband just looked like he was a deer in the headlights—he was just like sick to his stomach. Oh my gosh—it was so depressing." Furthermore, some parents (21%) reported that having other parents with children at the same stage of development was preferable.

Given that all participants had placed their child with SPIDD in out-of-home care, several parents (32%) discussed placement status and attitudes about placement as important considerations for support group composition. Some parents (16%) indicated that they did not want to be in support group meetings with parents who either had not placed a child or who would not consider placement because it evoked feelings of guilt rather than feelings of being supported and understood. These parents reported that they would have liked to have found a group composed of parents who had placed their children in out-of-home care because it was during and after placement that they needed the most additional support. A mother explained, "The support groups that we attended were support groups for people who still had their children in their home. I have yet to see a support group for people who have placed their children. I think people who've placed their children need a support group." Another mother echoed, "Had there been a support group of parents who had recently placed their children out of the home, I would have gone to it because it would have maybe helped me to get over some of the things that I struggled with inside sooner."

Meeting Content

Parents addressed the topics discussed in support group meetings, the format of discussions, and how support group meeting agendas and formats are determined. Parents were evenly split, with some parents (16%) preferring to have a place to share their experiences freely without a set agenda, and with other parents (16%) preferring that meetings have a jointly developed agenda based on group needs. Parents indicated it was important that the topics discussed in meetings be both applicable and interesting relative to their situations. As one mother said, "You need to try to find out what that [particular] group of people need." The topics and formats that parents discussed were coded into four categories: sharing experiences, sharing information, formal psychoeducation, and direction for advocacy.

The importance of support groups creating a space for parents to talk about their experiences with one another was expressed in almost every (80%) interview. One mother indicated, "I think probably the most beneficial would be to be in a setting in which you have the opportunity to discuss your issues, and your thoughts, and your feelings, and have somebody listen to you." For most parents, the value of sharing experiences stemmed from a desire to have their experiences normalized and to feel reassured and understood:

> It wouldn't have eliminated everything… But I would want to know how other people dealt with it. I would want to know about their successes. And for me, I'd want to know about the things they fought and struggled with, just to know that maybe somebody else had the same guilt and struggles, and once again it was normal because you always…think you're the only one that's ever felt that way—especially if it's negative—and to know that others have been there—it's a good thing.

Almost all parents (89%) reported that support groups should be "a place where you can go to gather information." Parents discussed wanting strategies from other parents and recommendations for obtaining services through social services and other agencies.

Many parents (53%) indicated that they would benefit from opportunities for them and other parents to share strategies that had helped them the complexities of raising a child with SPIDD. One mother shared, “Talking about the problems…each of us were having and to be able to help one another to see what ways we could help them from our experiences, then they could learn…how they can deal with them.” Parents discussed sharing strategies on topics such as “specific interventions,” ideas for “structured activities,” “how to help their [child’s] behavior,” and “places that you can go” with their child who has disabilities.

About half of parents (47%) discussed a desire to learn how to obtain support and services for their child with SPIDD. One mother shared that she would like to have received information on “support services and resources that are available to families…in the community… Show how systems work and how to work systems—how you can be an advocate for your child.” Several parents also reported that it would be helpful if support groups provided information about obtaining support from the school system. A father stated that it would be helpful if support groups provided “information about the responsibilities of the school system and how parents have to work with the school system to make sure the services are provided. Parents…need to understand what schools are responsible for and how to take on a school.” Finally, some parents suggested that referrals for professionals (e.g., medical care providers such as doctors and dentists, lawyers) who work with children with disabilities and information about respite care providers be shared among parents in support group meetings.

Most parents (74%) said that having specialists with expertise in disabilities provide formal psychoeducation about specific topics to the support group would be valuable. For example, parents suggested having a specialist on a specific disability come and share new research on topics like developmental trajectories and prognosis, and training on Medicaid and advocacy. A mother also suggested, “It would be great if it was also a place where they could go to obtain information on new products that are available, as far as assistive devices or maybe new treatments that are available now.” One mother underscored the importance that the information be presented in a way that made it accessible: “I’m not there for a medical degree or to get class credits or anything like that… You come away with a bunch of pamphlets and booklets, but nothing you really understand.” However, one set of parents explicitly preferred “not [to] have somebody up there lecturing,” instead favoring meetings dedicated to sharing between support group members. Two sets of parents suggested guest lectures be included either once every few meetings or that meetings be divided with half being for discussion and half being for a guest speaker.

Some parents (21%) discussed ways in which support groups could address issues of advocacy and help make changes to state and agency systems. One mother said of the support group she attended, “I think they did some good lobbying, and I really felt like that made a difference in the services that became available in this state… It was like a place where…there was a chance you could do something.” Another mother shared, “I don’t think any of us did it just for our own children; it was for others also. So it was a benevolent thing, too.”

Leadership

Several parents (26%) indicated a preference for a strong leader who could “pull it all together.” One set of parents shared that having a professional to “monitor [the support group meeting] and give you some suggestions” was helpful. One mother highlighted that strong committed leaders who are inclusive and non-judgmental is critical to the success of a support group:

> The people running the meeting did not want to hear any opposing points of view. So somehow I think these support groups need to be run by an unbiased person because otherwise, to me, it gets to be more concentrated on the person that happens to be running it and their point of view of what they think needs to happen.

Member Recruitment

Most parents (80%) discussed how they had either heard about support groups or means they recommended for outreach. The majority of parents who discussed recruitment suggested that a “central point” such as social services, state agencies, or local and national organizations, help connect parents to support groups. One father explained, “If you got a hold of one agency, they ought to suggest, ‘You ought to consider this…’ I’m not sure many people on their own would [attend] unless you’ve talked to someone.” Parents suggested that hospitals, medical professionals, caseworkers, out-of-home placements, and other service providers such as school administrators and teachers who work with children with disabilities refer parents to a local support group. Other recommendations included advertising through print (e.g., newsletters, mail), electronically (e.g., websites, email), and word-of-mouth among parents.

Discussion

Parents of children with SPIDD wanted support groups to be a place where they could feel understood and learn how to better support their child with SPIDD. Prevalent themes included a desire to both feel understood and obtain information. Consistent with previous research, parents valued learning from peers, exchanging ideas, and sharing strategies in support groups (Law et al. 2002), which they associated with easing uncertainties and fostering a sense of empowerment (Solomon et al. 2001). Not all parents in this study, however, perceived support groups to be valuable; parents who did not think support groups are valuable typically had never attended a meeting. One of the contributions of the present study is that participants included both parents who had attended support groups as well as parents who had not, which may account for the varied assessments of support group value among parents. Many (64%) of the parents who did not attend support groups did not believe they are valuable, whereas a majority (84%) of parents who had attended support groups believed support groups have at least some inherent value inherent.

Whether support groups were perceived as a valuable resource was ultimately based on the degree to which support groups addressed the parent's needs. In line with previous research (Jones and Passey 2004), parents who reported that support groups were valuable indicated group participation helped address the stressors of having a child with SPIDD, whereas parents who reported support groups were not valuable indicated support groups made them feel indifferent or even worse about their situation.

Two different patterns of parallel opposites emerged from parents discussing why they valued—or did not value—support groups and what they recommended in terms of support group design. The first pattern consisted of parents wanting the same things out of support groups but discussing those things in opposite ways. For example, feeling understood and feeling a sense of belonging was the most commonly cited reason that parents found support groups be helpful; conversely, poor fit due to not feeling understood was the most commonly cited reason why support groups were not seen as helpful or valuable. Another example of parents expressing similar concepts in opposite ways was indicating that support groups provide extra needed social support, or the opposite that they did not believe there was a need for additional social support.

The second pattern that emerged was parents having opposite preferences from one another. For instance, some parents believed that being in a support group with parents facing similar challenges was an opportunity to learn from others and help each other; other parents believed that being in a support group with parents dealing with similar challenges would create a situation in which they may compare themselves in ways that would make them feel worse rather than better. Because parents frequently expressed opposite preferences around support group design—the very things that some parents wanted were exactly what other parents did not want—the following recommendations for support groups design were developed to provide concrete suggestions aimed at meeting a wide variety of needs and preferences (Table 1).

Group Structure Recommendations

Parent sensitivities to time away from their child with SPIDD and other children was often what guided their recommendations around the ways support group meetings should be structured. The length of meetings was a significant factor because it was a set amount of time that they knew they would be away from their children, which frequently required finding additional care resources to attend a support group. In an effort to minimize the time away and childcare dilemma, parents suggested that *support groups offer concurrent child-care services both for children with disabilities and siblings of children with disabilities*. Services might include respite care or recreational therapy for the child with SPIDD and workshops or support groups for their siblings. In addition, parents generally recommended that *support group meetings run 60–90 min* to decrease depletion of childcare resources they might need to attend.

Parents recommended a variety of different meeting schedules ranging from weekly to once every 6 months that were similar to that which is found in the literature (Hammarberg et al. 2014; McCabe and McCabe 2013). Most parents suggested a meeting frequency of once to twice a month. Meeting time and location were cited as common reasons parents had difficulty attending meetings, which is also consistent with previous findings (Wynter et al. 2015). Furthermore, irregular attendance is a common problem in support groups and is one of the most likely reasons that they disband (Galinsky and Schopler 1994; Wituk et al. 2002). Therefore, we recommend *support groups have scheduled meetings twice a month, on different days, and at different times, and locations*. Ideally, the two bi-monthly meetings would each be scheduled on different days of the week, at different times, and at different locations so that if a parent cannot attend the first meeting of the month due to logistical barriers, they might be able to attend the other. We also recommend *support groups be open, allowing members the flexibility to attend as needed and when convenient*. Structuring groups as open allows parents who only want to attend once a month, once a quarter, or even less frequently the flexibility to do so. Given time is a significantly limited resource for parents of children with SPIDD (Bull 2003), additional structure options that may provide parents flexibility include participating remotely via phone and videoconference, or independently scheduling one-to-one peer support meetings outside of the larger group based on individual schedules and availability.

Table 1 Support group design recommendations

Design element	Recommendation
Meeting length	Total meeting length of 60–90 min with possibility of splitting meeting in to two, shorter meetings (either for different formats or for subgroup meetings) of 30–45 min each
Frequency	Meetings scheduled twice a month; adjust as needed to maintain group size
Format and duration	Open ongoing group; one-to-one parent pairs
Accessibility	Offer alternative meeting times and locations with first meeting of the month scheduled on a different day and time than second meeting to increase flexibility in attendance (e.g., meeting one on the first monday of the month in the evening; meeting two on the last saturday of the month in the morning); option to participate remotely
Concurrent services	Offer groups for siblings of children with disabilities occurring at the same time as support group meeting; offer additional childcare for siblings not participating in group and respite care services for children with disabilities
Additional resources	Groups should serve as a hub to direct parents to other parents (one-to-one), other services, or other support resources that may be beneficial to them
Size	Approximately ten parents in group meetings; adjust meeting frequency to maintain size
Children's disability	Children of parents in the support group have similar severity of disability; children have the same disability, or have similar types of impairments (e.g., all have cerebral palsy, or all have severe physical limitations)
Children's age	Include either parents of children of various ages or of similar ages; include session topics, guest speakers, or parents with additional experience as appropriate
Placement status	Parents of children who have placed their child should have a separate group or separate subgroup to address their specific needs
Agenda	Parents have input on meeting agendas and are provided with possible meeting topic options; schedule is created so parents can determine which meetings they want to attend; if meetings are split by subgroup, topic, or format (discussion or psychoeducation), parents may choose to attend one or both shorter meetings
Discussion	At least half (30–45 min) of the total meeting is devoted to parent discussion; parents may decide on discussion topics that address their personal experiences as well as allows a space to share information and hear about strategies other parents have used to address specific issues
Psychoeducation	Guest speakers are scheduled based on parent interests; option for half (30–45 min) of full session; possible examples include legal professionals, medical professionals, financial experts, activists, etc.
Facilitation and leadership	Support group should have a facilitator who organizes and maintains the structure, composition, and content of group meetings; facilitator should be collaborative and trained though does not need to be a helping professional
Advertising	Support group should advertise by as many means as possible, including schools, hospitals, state agencies, and direct outreach; advertising should include group schedule, topics of discussion, and other significant information (e.g., information about leadership, target audience, parent characteristics)

Group Membership Composition Recommendations

The majority of parents who addressed group size were either comfortable with or preferred meetings attended by fewer than ten parents to facilitate intimacy and connection. Corresponding research suggests the ideal group size is five to ten members because it facilitates group cohesion and beneficial interaction (Yalom and Leszcz 2005). Consequently, *the recommended target group size should be approximately ten parents per meeting*. By nature of groups being open, attendance will inevitably vary meeting to meeting as not all parents will attend all meetings (Wituk et al. 2002).

About two-thirds of parents discussed that sameness among group members was one of the more important aspects of support group composition. Because the degree of sameness was often linked to the desire to feel understood, we recommend *support group membership be relatively homogenous in relation to the type and severity of the children's disabilities*. Consistent with previous literature, most parents preferred that meetings be composed of parents who have children with similar disabilities that are similarly severe to foster a sense of belonging and encourage social support from others in comparable situations (McCabe and McCabe 2013; Wynter et al. 2015). In addition, the more similarities parents share, the more likely it is that the advice and information they share will be applicable (Robert et al. 2015).

Although some parents expressed a desire to be with parents who were at later stages of family life whose children with disabilities were relatively older, they did not seem willing to be the parent with that distinction. A common problem of open groups is that members may be dealing with different struggles because they are at different stages and have varied experiences (Galinsky and Schopler 1994). Because parents were evenly split on whether they wanted to be with parents of children at the same or different ages, rather than restricting group membership, we recommend that *support group leaders note differences in parent experience and compensate for parent needs accordingly*. For example, in a support group with parents whose children are at different stages of development, group leaders may consider having more experienced parents serve as mentors or co-facilitate meetings. Conversely, in groups where parents are similar in age, guest speakers could specifically address what parents can expect in the future.

We also recommend that *parents who have placed a child, or who are considering placing a child in out-of-home care, have a distinct support group or subgroup*. Several parents reported that the needs of parents who are still caring for their child at home may be significantly different than those who are utilizing out-of-home care (Roper and Jackson 2007). Therefore, as a number of parents suggested, they may be better served in a group or subgroup that specifically addresses challenges associated with placing a child. In addition, parents recommended that *the topic of placement be incorporated in support group meetings for parents who had their children in the home*. For instance, some parents recommended that it may be helpful to discuss placement in support group meetings, or have parents who have placed a child come as a guest speakers.

Depending on the community or location of a support group (e.g., rural versus metropolitan), it may not be feasible to have groups of the recommended size of ten members with very specific shared characteristics (e.g., type and severity of disability, level of experience, placement status). In cases where support groups may need to be composed of parents with wider-ranging characteristics, we recommend *the formation of shared-characteristic subgroups*. Subgroups might meet for a portion of one or both of the twice-monthly meetings, or schedule additional times to meet. If there is insufficient membership to support subgroups, one-to-one peer support with one or two sets of parents who share key characteristics may prove beneficial.

Meeting Content Recommendations

The content of support group meetings was one of the most significant aspects of support group design. In concert with previous research (Diehl et al. 1991; Wynter et al. 2015), parents expressed a desire to (a) share experiences and practical advice and (b) receive relevant and useful information on key topics. In terms of structured information dissemination (e.g., guest speakers), some parents were in favor and other parents were opposed. Accordingly, with a bi-weekly 90-min session structure in mind, we recommend that *each support group meeting be divided into two parts: formal psychoeducation and discussion*. By dividing the meeting, parents have the option to attend the portions of the meeting that best serve their needs. Because some parents explicitly did not want to share their experiences and some parents explicitly did not want to be given advice, one solution is focusing the discussion portion of the first meeting of the month on sharing experiences and the second meeting of the month on sharing advice, with the same formal psychoeducation portion at both meetings. Support group meetings should also include discussions on how parents can advocate for their families for policy changes and systemic changes in the delivery of disability services. In addition, parents who prefer more discussion (on top of what is provided in the larger group meetings) may opt to network with other parents from the group in a one-to-one setting.

Consistent with previous research (Bull 2003; Nicholas and Keilty 2007; Robert et al. 2015), the content of support meetings was a significant factor for parents as they often had varied needs and wanted meeting content to suit their needs. One way to address meeting content applicability issues is to have *parents select topics that would be most helpful to them*. To help parents identify the most important topics to them, group leaders could provide a list of relevant discussion and psychoeducation topics from which parents select those of greatest interest (Table 2). After parents have provided input on preferred meeting topics, group leaders should *create and distribute a schedule indicating which topics will be addressed on which days so that parents can choose* to attend meetings with topics that are the most germane to them (King et al. 2000).

Parents need an array of different and flexible resources and it is important that a support group be designed to provide parents with information on relevant resources (Nicholas and Keilty 2007). *Support groups should serve as a hub of resources* for parents of children with disabilities. Parents often described that services were decentralized and that it was difficult to connect to other parents in similar circumstances or to adequately navigate service delivery systems. Therefore, in addition to serving as a resource, the ideal support group would also direct parents to other beneficial resources and services.

Meeting Leadership and Facilitation Recommendations

Only a few parents discussed the aspect of support group leadership, suggesting it was a less significant factor in group design. Parents generally felt it was important to have a leader with specific qualities (e.g., unbiased, committed, enthusiastic). Additionally, previous research indicates that parents value effective facilitation ability (e.g., empathy, guiding meaningful conversations) over whether the facilitator is a professional or a peer (Hornby 2014; Kingsnorth et al. 2011). Therefore, *support groups should have a specified leader (or co-leaders) who have had some type of training in group facilitation*.

Table 2 Support group meeting agenda options

Discussion topic (30–45 min)
• Open discussion: no predetermined topic for the meeting; parents can discuss different topics at will
• Addressing anxiety: share experiences with anxiety and coping strategies
• Managing guilt: share experiences with guilt and coping strategies
• Success stories: share stories of hope and encouragement; positive experiences
• Frustration at home: discuss struggles and challenges that appear in the home environment
• Addressing partner relationships: discuss challenges and successes in your relationship with your partner
• Networking with other parents: discuss relevant opportunities or activities with other parents
• Time management: share experiences and strategies for balancing multiple responsibilities
• Navigating the state social service system: share experiences and strategies for obtaining public services
• Navigating the school system: share experiences and strategies for obtaining education services
• Finding service providers: discuss experiences working with various professionals (e.g., therapists, doctors, lawyers) and share referrals
• Addressing the community: share experiences and strategies for dealing with neighbors or other community members (e.g., friends, clergy, teachers)
• Thinking about out-of-home placement: discuss the emotional and logistical aspects of placement
Guest speaker/training (30–45 min)
• Advocacy and lobbying: hear from local government representatives or rights activists for persons with disabilities
• Guardianship and other legal issues: hear from lawyers and legal experts on pertinent legal issues
• Treatment: hear from medical professionals, psychotherapists, speech language pathologists, and occupational therapists on new or existing treatments for specific symptoms or specific disabilities
• Developmental expectations: hear from medical professionals (e.g., doctors, occupational therapists) on what to expect regarding your child's growth and development
• Financial management: hear from financial experts (e.g., accountants, financial planners) on ways to manage finances currently and in the future
• Navigating the state social service system: hear from experienced parents and local representatives for ways to access public services
• Navigating the school system: hear from experienced parents, teacher and school administrators about what to expect from the school system
• Out-of-home placement information: hear from parents who have placed, professional parents, and from representatives from local placement locations (e.g., group homes, residential care centers)
• Stories from experienced parents: hear personal stories from parents of older or adult children with intellectual and developmental disabilities

Example agenda topics are grounded in the data and generated based on parent experiences and suggestions

Member Outreach Recommendations

Parents suggested a variety of ways to reach out to potential group members through social services, schools, and direct advertising (Mohr 2004; Wituk et al. 2002). We recommend that *outreach to parents, whatever the means, directly address some of the concerns expressed by parents who did not feel support groups would be valuable*. One suggestion for addressing parent concerns in the outreach process is to include a description of support group design and details about session content as a part of advertising.

Limitations

One of the primary limitations of this study is that most participants were Caucasian, married, and identified as Mormon, significantly constraining the generalizability of the findings. Additionally, all participants resided in Utah; since many services provided for parents of children with SPIDD are administered at the state level, results may have varied if participants from other states had been included (e.g., parents in other states may receive different types of resources, altering their needs and what they would like from support groups). Furthermore, participants were parents who had placed their child with SPIDD in out-of-home care. Although participants who had attended support groups were more frequently reflecting on their experiences prior to placing their child than their experiences after placing their child, conducting a similar study with parents who had not placed their children may yield different results, particularly in relation to the resources parents reported they needed the most (Werner et al. 2009). Although one strength of the present study is that the sample included parents who had both attended and not attended support groups, it is possible that the recommendations provided by parents who had not attended were more subjective because they were not grounded in specific experiences. Furthermore, for participants who had attended a support group, data on the nature of those support groups, including their structure and facilitation, were not collected, thus preventing analysis on common factors that either added or detracted value.

Directions for Future Research

Similar studies with more heterogeneous participants in different geographical locations should be conducted to confirm or disconfirm the results of this study. Subsequent research should replicate this study with parents who are caring for their child at home to understand their recommendations for support group design. In addition, future research may incorporate online support groups and online forums, which are becoming more prevalent (Clifford and Minnes 2013). Finally, subsequent research should design and conduct support groups using the recommendations that have been generated from this study; those groups should then be assessed and evaluated to determine if the groups meet the needs of the members.

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Compliance with Ethical Standards

Conflict of interest The authors declare they have no potential conflict of interest relevant to this study.

Ethical Approval All procedures performed in studies involving human participants were in accordance with the ethical standards of the institutional and/or national research committee and with the 1964 Helsinki declaration and its later amendments or comparable ethical standards. This article does not contain any studies with animals performed by any of the authors.

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