# But... How Helpful is That? Parents' Views on the Helpfulness of Selected Resources When Making Educational Decisions for Their Young Children with Disabilities

María Isolina Ruiz, Ph.D. University of Louisiana at Lafayette

Linda Flynn-Wilson, Ph.D. University of New Orleans

Lauren Giovingo, Ph.D. Philip G. Wilson, Ph.D. Louisiana State University

#### Abstract

Q-methodology was used to explore parents' views on the helpfulness of selected resources when making educational decisions for their young children with disabilities. Parents' determination to get what was best for the child and school staff who understood the child's disabilities averaged the highest scores. Children's age and type of disability seemed to influence parents' perceptions of the helpfulness of specific resources. However, participants agreed that each one of the selected resources could be helpful to them at some point in their journey to secure adequate education and services for their children. By-person factor analysis identified three distinctive viewpoints on the helpfulness of resources presented to participants: a) using a balanced combination of internal and external resources, b) preference for internal or within-parent resources, and c) a focus on external resources. Parents suggested other resources that they thought would help them when making decisions about their children's education.

Key words: resources, educational decisions, parents, young children with disabilities

# But... How Helpful is That? Parents' Views on the Helpfulness of Selected Resources When Making Educational Decisions for Their Young Children with Disabilities

Participation in the educational decision-making process is by far the most distinctive component of parental involvement among parents of children with disabilities. While parental involvement in school-related activities has an undeniable positive effect on the academic achievement of children with disabilities (McDonnall, Cavenaugh, & Giesen, 2010; Miedel & Reynolds, 2000; Trainor, 2010a), the repercussions of parental participation on these students go beyond what most professionals picture when thinking of typical children. Besides being a legal right (IDEA, 1997; IDEIA, 2004), parental participation in decisions regarding the education of young children with disabilities has the potential to increase school personnel's compliance with the special education process. In turn, this may improve the quality of the education that the student receives (Trainor, 2010b) and reduce parental stress (Burke & Hodapp, 2014). Unfortunately, being part of the educational decision-making process can be a daunting task for parents due to their limited expertise in matters related to the education of children with disabilities (Hughes,

Valle-Riestra, & Arguelles, 2008; Olmstead et al., 2010) and the multiple challenges associated with raising a child with a disability (Breitkreuz, Wunderli, Savage, & McConnell, 2014; Vanega & Abdelrahin, 2016). As a result, each parent must develop his or her plan of action for approaching such decisions: they identify *internal* (within-parent) and *external* (outside-parent) resources available to them and choose when and how to use them.

### A Word on Advocacy

Parents' participation in educational decisions about their children with disabilities is often viewed as advocating for the child. Despite the term not being specified in the law, some experts agree that the spirit of the Individuals with Disabilities Education Act, or IDEA, implies the exercise of parental advocacy (Kalyanpur, Harry, & Skrtic, 2000; Trainor, 2010a). IDEA requirements (e.g., necessary parental consent before evaluation placement of children in special education) compel parents to constantly consider how their children's educational needs will be addressed. Throughout this process, parents are expected to share their impressions about their children's strengths and weaknesses and to collaborate with professionals in selecting the best educational approach and services for their children. This form of involvement is not usually expected of parents of children without disabilities.

Parents' abilities to advocate for their children with disabilities can vary significantly. Trainor (2010b) described four approaches to parental involvement among parents of children with disabilities: (a) the intuitive advocates, (b) the disability experts, (c) the strategists, and (d) the change agents. Each approach involves varying levels of involvement in educational decisionmaking and styles of advocacy. For instance, intuitive agents share knowledge about their children with disabilities (e.g., preferences, dislikes, talents) with educators. Unfortunately, due to the tendency among professionals to disregard this type of information, these parents' participation in educational decisions is limited. Disability experts incorporate knowledge of their children's disabilities into their interactions with school professionals and seek to connect with other parents of children with disabilities to combat feelings of isolation. They are actively involved in deciding about their children's education and are more likely to develop a collaborative relationship with professionals than their intuitive counterparts. Strategists are very knowledgeable about laws and procedures and have a thorough understanding of their rights to advocate for their children with disabilities. They regularly supervise their children's educational programs to ensure they are being followed and create a place for themselves in the decision-making process. Last, change agents go beyond advocating for their children; they pursue systemic changes and sacrifice personal time to secure a better experience for other families. According to Trainor, these four approaches are used by parents across race and ethnicity, with socioeconomic status and type of disability (especially autism) being the most influential factors in parents selecting one approach or the other. That is, although greater levels of advocacy usually result in more effective parental involvement and better educational outcomes for young children with disabilities, not all parents engage in the same manner in the decision-making process nor rely on the same resources when making decisions about the education of their children with disabilities.

# **Selecting Resources**

Research has shown that parents of young children with disabilities use a myriad of resources (i.e., supports and strategies) when deciding about their children's education. Although all

resources identified by research are presumably valuable, parents rely on some resources more than others depending on their personality, the availability of each resource, the current needs of the child, and their family culture, among other factors. Tetreault et al. (2014) identified nine types of supports available to parents of children with disabilities: informational support; assistance and support with decision making; legal support; financial support; educational support; psychosocial support; assistance with daily living activities; leisure, sports, and social activities interventions; and transportation. Parents of young children with disabilities usually rely on family members and close friends for emotional support and practical help (e.g., babysitting, running errands related to the child) and count on professionals to provide information and technical assistance for meeting their children's needs (Garwik, Patterson, Bennett, & Blum, 1998; White & Hastings, 2004). They may view staff from the agencies servicing their children and families (Hiebert-Murphy, Trute, & Wright, 2011; Litt & McCormick, 2015; Sloper, Greco, Beecham, & Webb, 2006), as well as professionals consulted outside school (Brown, Moraes & Mayhew, 2005; Heiman, 2002; Rahi, Manaras, Tuomainen, & Hundt, 2004; Sheppard & Vitalone-Raccaro, 2016), as sources of support in understanding their children's health and educational needs. At the same time, parents may view family support services as a resource that helps them enhance their sense of well-being (Freedman & Boyer, 2000) and ability to cope with the trials and tribulations that usually come with having a young child with disabilities. Parents may view school personnel as valuable resources, especially if schools make their family's expectations and dreams for the child a priority, and respect for the family's culture and values is evident during educational planning (Bailey, Hebbeler, Scaraborough, Spiker, & Mallik, 2004; Burke & Hodapp, 2014; Fish, 2008). As their trust in school personnel's knowledge about the child's disability (Hess, Molina, & Kozleski, 2006) and special education laws (Lake & Billingsley, 2000) solidifies, parents might expect educators to teach them about their children's educational needs and the procedures involved in making adequate and responsive decisions for their children (Hughes et al., 2008; Zionts, Zionts, Harrison, & Bellinger, 2003). Also, whether it is through participation in support groups (Mandell & Salzer, 2007) or more casual conversations (Ainbinder et al., 1998), parents may depend on formal and informal interactions with other parents of children with disabilities, to access information and supports that professionals and family members cannot provide.

Besides using the resources mentioned above, parents of young children with disabilities often turn within themselves for inspiration. They make use of their inner strength, motivation, and personal strategies to support themselves through the educational decision-making process. Parents' inner strength, positive emotional state, and determination to secure necessary services for their children help them persevere in their efforts to be active participants in all aspects of their children's lives, including their education. For example, research has shown that, compared to parents with pessimistic views of their child's disability, parents who are curious about it, and resolute to do what is best for the child, participate more in their children's education (Granger, des Rivieres-Pigeon, Sabourin, & Forget, 2010; Ingber, Al-Yagon, & Dromi, 2010). These internal resources can facilitate parents' participation in educational decisions about their children while improving their abilities to use external resources. Similarly, parents' subjective perceptions of professionals' attitudes toward their child and family influence the choices they make for their children (Zionts et al., 2003) and willingness, or lack thereof, to collaborate with schools (Lake and Billingsley, 2000). Finally, their understanding of their children's disabilities (Brown et al., 2005), special education laws (Fish, 2008; Spann, Kohler, & Soenksen, 2003), and

available services and programs (Hess et al., 2006) can ultimately empower parents to advocate and make sounder educational decisions for their children (Trainor, 2010b).

Parents' choice to rely on a particular resource might indirectly affect the decisions they ultimately make for their children. While not all parents of young children with disabilities have access to every identified resource, they are likely to have a viewpoint about how specific resources would help them decide about their children's education. To facilitate parents' involvement in their children's educational decision-making process, professionals providing health, psychological, social, or educational services to young children with disabilities and their families must understand the value that individual parents are likely to assign to different resources.

This study aimed to explore parents' viewpoints on the relative helpfulness of selected resources when making educational decisions about their young children with disabilities. The following research questions guided our inquiry:

- What resources do parents find most helpful when making educational decisions for their young children with disabilities?
- What factors influence parents' views on the helpfulness of particular resources when making educational decisions for their young children with disabilities?
- How do viewpoints about the helpfulness of selected resources vary among parents of young children with disabilities?

#### Method

#### **Participants**

A purposive sample was used. Twenty-one (n=21) caregivers (20 parents and one grandparent acting as the legal guardian) of 3 to 5-year-old children with disabilities who received special education services in eight school districts within a single state were chosen as participants. Recruitment was open to parents of all racial, ethnic, and socioeconomic backgrounds. Participants were recruited through local clinics, family advocacy agencies' social media, a local newspaper, and newsletters from universities to which researchers were affiliated. Because this project was completed in the summer, schools and early childhood centers were not included. Although not a criterion for participation, all participants reported having interacted with an advocacy agency or support group since their children's disability diagnosis. Participation in this study was voluntary, and no compensation for participating was provided. For this study, all participants were referred to as *parents*. All parents kept their participant status throughout the project.

Eighteen participants were female, and three were male. Most participants (n=17) were Caucasian, two were African-American, and one was Latino. One participant did not disclose her ethnicity. Participants were relatively young, with only three being 45 years old or older. All participants had post-high school education or had graduated from a higher education institution. Participants' children with disabilities consisted of 10 girls and 11 boys; they were three (n =7), four (n=7), or five (n=7) years of age. Participants' children had diagnoses of autism (n=10), developmental delay (n=3), intellectual disabilities (n=4), physical disabilities (n=3); and multiple disabilities, reported by the parent as a "combination of developmental delay with orthopedic and visual impairments", (n=1).

#### **Procedure**

Q-methodology was utilized to collect and analyze data on parents' views on the helpfulness of selected resources when making educational decisions for their children with disabilities. Q-methodology is a ranking technique used to identify an individual's subjective viewpoint on a topic (McKeown & Thomas, 1988). The goal of Q-methodology is not to generalize findings to a population but to develop insight about different points of view that groups of people may have about a particular subject (Coogan & Herrington, 2011; Watts & Stenner, 2012). Studies using Q-methodology typically have samples of 20 to 100 participants (Tractinsky & Jarvenpaa, 1995); thus, the use of small samples is considered appropriate in studies involving Q-methodology.

Q-methodology has been used to collect data in studies involving families of children with and without disabilities (e.g., Ayvazoglu, Oh, & Kozub, 2006; Bakermans-Kranenburg, van IJzendoorn, Bokhorst, & Schuengel, 2004; Caldera & Lindsey, 2006; Gane et al., 2010; Roberts, 1986; Stanley-Gane, Flynn, Neitzel, Cronister, & Hagerman, 1996). It is a valuable tool for collecting information in early intervention because of its ability to assess individuals' predilections and shared perspectives along a continuum of significance (Sexton, Snyder, Wadsworth, Jardine, & Ernest, 1998), which makes it a perfect choice for the present study.

Consistent with Q-methodology, a Q-set was created to represent selected resources, and a Q-sort was used to collect data. Q-methodology then provided a structure for forcing participants to rank the helpfulness of the selected resources when making educational decisions for their children with disabilities, even if they had previously perceived them as being similarly helpful (Stephenson, 1953). Also, Q-methodology allowed us to explore participants' viewpoints holistically and to look closely at the resources that may seem helpful to different groups of parents.

**Q-set design.** As part of creating the Q-set for this study, the researchers conducted a review of the literature. Internet searches of ERIC, Google Scholar, Questia, and MEDLINE were performed using combinations of keywords: "helpful", "resources", "supports", "strategies", "challenges", "parents/families", "children with disabilities", "education", and "services". The articles selected described a) resources used by parents while navigating the special education system and coping with their children's disabilities, or b) challenges faced by parents while taking part in the special education process.

Ultimately, the review consisted of 30 articles published in 25 professional journals in special education, psychology, and health sciences. Information on parents' resources was summarized and used to generate the items in the Q-set. An initial set of 31 items was created. A panel of special educators, related services professionals, and parents of children with disabilities who would not be participating in the study examined the items to determine their social validity. Items were combined or restated to represent distinctive resources. Statements were written in a positive tone to avoid introducing bias into the sorting procedure. After multiple revisions, 16 items remained. Each item was printed on a separate card. The final Q-set comprised five internal and 11 external resources.

**Q-sort administration.** Three researchers were trained in the Q-sort administration technique to ensure consistency in data collection. To facilitate participation, data were collected at a location

selected by each family. Participants were asked to read all Q-items and think of those statements as resources that might be helpful to them when making decisions about their children's education. Then, the researchers read scripted instructions aloud to guide participants through the ranking of resources. Each column on the Q-sort represented a value ranging from one, least helpful, to 7, most helpful (see Figure 1). Items were assigned the value that matched their placement on the Q-sort. Q-sort data were transferred to a data sheet. Data sheets were numbered to ensure anonymity, and demographic information was collected.

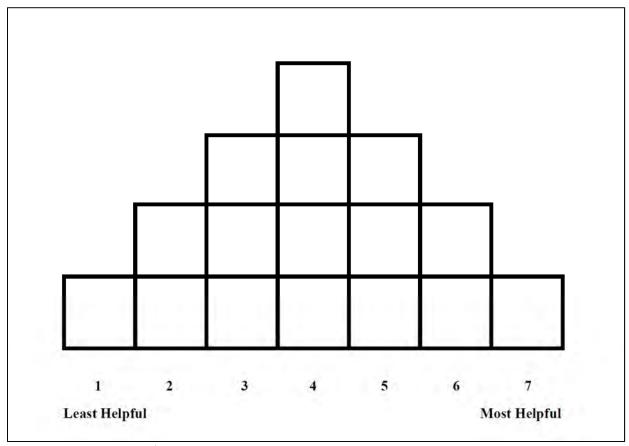


Figure 1. Q Sort Board

After completing the Q-sort activity, parents had the opportunity to share commentary on the selected resources or to suggest other resources that were, or would be, helpful to them when making educational decisions for their young children with disabilities. The researchers recorded participants' comments and suggestions for future analysis.

## Data Analysis

Descriptive statistics were used to determine the items that ranked highest and lowest among participants. Mean, mode, standard deviation, and percentages were calculated for each item. Based on these data, a general ranking was generated to show resources found to be most-to-least helpful to parents when deciding about their children's education. Possible associations between demographic information and participants' ranking of resources were explored.

To develop insight into individual participants' viewpoints on the helpfulness of the selected resources when making educational decisions for their children with disabilities, Q-sort data were entered into the PQ Method, a statistical analysis software dedicated to Q-methodology. Q-sorts were intercorrelated and factor-analyzed following the *factor-per-number of participants* guidelines provided by Watts and Stenner (2012). Factors were inspected for eigenvalues of 1 or higher (Kaiser-Guttman criterion) and the presence of at least two highly loaded Q-sorts (Brown, 1980). A Varimax rotation was performed, and a correlation matrix of all Q-sorts was created using a by-person factor analysis to compare the viewpoints collected in the Q-sorts. Single Q-sort configurations representing each factor (i.e., factor arrays) were calculated using a weighted averaging procedure and used as the basis for interpreting the data provided by that factor. Finally, the preferences of participants whose Q-sorts loaded (i.e., were highly correlated) in a factor were summarized in a narrative describing the viewpoint expressed by that factor. Demographic information was included to aid interpretation.

Comments about selected resources and suggestions for additional resources made by participants after completing the Q-sort were segmented and organized using an open coding system (Creswell & Poth, 2017). Comments and suggestions were assigned to separate categories. Within each category, participants' contributions were grouped into themes. Data were analyzed for contributing factors or intervening conditions that might have influenced participants' responses and for information that could facilitate the interpretation of the viewpoints identified during the analysis of Q-sort data.

## **Findings**

## **Most Helpful Resources**

Overall, having school staff who understood the child's disability and parents' determination to get what was best for their children received the two highest scores, making them the most helpful resources for parents when deciding about the education of their young children with disabilities. Resources considered least helpful included parents' involvement with support groups; having school staff who respected families' values and cultures; and educators' understanding of special education laws. Standard deviations for Q-sort items ranged between 1.1 and 1.97, suggesting low to moderate variability among participants' rankings (see Table 1).

Table 1
Overall Resource Ranking

Ranking	Item Description	М	SD	Mode	Top Three %	Bottom Three
1	School staff who understand my child's disability. (E)	5.38	1.24	6	76	5
2	My determination to get what's best for my child. (I)	5.38	1.26	5	71	0
3	My understanding of my child's disability and needs. (I)	5.00	1.18	4	57	5
3	My knowledge about services and programs for my child. (I)	4.57	1.16	5	57	19
3	School staff who include me as an equal member of the team. (E)	4.33	1.46	5	57	24
4	A positive attitude from school staff about my child and family. (E)	4.62	1.43	5	52	24
5	School staff who have high expectations for my child. (E)	4.24	1.14	5	47	24
6	School staff who work together as a team. (E)	4.24	1.26	4	38	24
7	Someone I trust who helps me make decisions about my child's education. (E)	3.76	1.97	3	33	57
8	School staff who care about my dreams for my child. (E)	3.71	1.1	3	19	47
8	My understanding about the special education law. (I)	3.62	1.56	4	19	43
8	My understanding of parents' rights and responsibilities. (I)	3.57	1.28	4	19	57
8	Discussions with professionals outside the school. (E)	3.43	1.5	3	19	43
9	School staff who understand special education laws. (E)	2.95	1.36	3	10	76
9	School staff who respect my family's values and culture. (E)	2.67	1.28	2	10	81
9	My involvement with parent support groups. (E)	2.52	1.47	2	10	71

# **Factors that Possibly Influenced Parents' Views on Resources**

Once data were disaggregated by age and type of disability (autism, cognitive and physical disabilities, and speech and language disorders) of participants' children, minor but tangible differences in the rankings of resources among subgroups became evident. For example, compared to parents of four and five-year-olds, parents of three-year-olds gave higher rankings to resources such as determination to get what was best for the child and knowledge of services

and programs. At the same time, parents of five-year-olds were the only group ranking understanding of the special education law as one of the top-three helpful resources (see Table 2).

Table 2
Resources Ranked by Child's Age.

Child's Age	Most Helpful Resources	Least Helpful Resources		
3	<ol> <li>School staff who understand my child's disability.</li> <li>My determination to get what's best for my child.</li> <li>My knowledge about services and programs for my child/ My understanding of my child's disabilities and needs.</li> </ol>	<ol> <li>My involvement with parent support groups.</li> <li>School staff who understand special education law / School staff who respect my family's values and culture.</li> </ol>		
4	<ol> <li>School staff who understand my child's disability.</li> <li>School staff who include me as an equal member of the team.</li> <li>Someone I trust who helps me make decisions about my child's education.</li> </ol>	<ol> <li>My involvement with parent support groups.</li> <li>School staff who understand special education law.</li> </ol>		
5	<ol> <li>School staff who understand my child's disability.</li> <li>My understanding of special education law.</li> <li>My understanding of my child's disability and needs.</li> </ol>	<ol> <li>School staff who respect my family's values and culture.</li> <li>My involvement with parent support groups.</li> <li>Discussions with professionals outside school / Someone I trust to help me make decisions about my child.</li> </ol>		

Additionally, variations were noticed in parents' assessments of the helpfulness of certain resources according to their children's disabilities. Specifically, school staff's understanding of the children's disabilities was ranked as one of the three most helpful resources by 70% of parents of children with autism compared to only 36% of parents of children with cognitive and physical disabilities.

## Parents' Viewpoints on the Helpfulness of Resources

Analysis of the distribution obtained from participants' rankings shed light on parents' viewpoints regarding the helpfulness of selected resources when making educational decisions

for their children with disabilities. Four factors were initially extracted. Nevertheless, after inspecting factors for eigenvalues and the presence of highly loaded Q-sorts, one factor involving five participants was excluded for not meeting criteria. Sixteen (n=16) of the 21 Q-sorts loaded significantly on one of the three remaining factors which, together, accounted for 56% of the variance (see Table 3).

Table 3
Factor Q-Sort Values for Each Statement

	g-son values for Each statement	Factor Arrays		
		Factor 1	Factor 2	Factor 3
Item	Statement	Balanced	Up to us	All about
#		combination	parents	them
			Scores	
1	School staff who understand my child's disability.	7	4	5
2	School staff who understand special education laws.	2	4	2
3	My understanding about the special education law.	2	7	3
4	My understanding of parents' rights and responsibilities.	3	5	3
5	My knowledge about services and programs for my child.	5	6	4
6	My understanding of my child's disability and needs.	6	5	3
7	Discussions with professionals outside the school.	3	3	4
8	School staff who work together as a team.	4	5	6
9	School staff who include me as an equal	4	4	7
	member of the team.	•	-	,
10	Someone I trust who helps me make decisions about my child's education.	5	2	1
11	My involvement with parent support groups.	1	3	2
12	School staff who have high expectations for my child.	4	4	5
13	School staff who care about my dreams for my child.	4	3	6
14	School staff who respect my family's values and culture.	3	1	4
15	My determination to get what's best for my child.	6	6	4
16	A positive attitude from school staff about my child and family.	5	2	5

Significant correlation coefficients between variables and factors ranged from .50 to .85; sixty-three percent of the factors loaded within the p < .01 significance level (.65 or higher). The viewpoints identified in the analysis included:

A balanced combination of internal and external resources. This viewpoint found parents' internal resources to be as helpful in making educational decisions for their children with disabilities as external resources accessed through professionals and specialized social networks. Nine participants (n= 9) shared this viewpoint, which had an eigenvalue of 7.00 and explained 26% of the study variance. Parents identified themselves as Caucasian; seven were female, and two were male. Their average age was 36 years, and the average age of their children was three years and ten months. Five of the children were boys, and four were girls. Six of the children had autism, and three had orthopedic impairments or intellectual disabilities.

Parents sharing this viewpoint considered their understanding of the child's disability and needs (6: 6), determination to obtain what was best for the child (15: 6), and knowledge of services and programs (5: 5) to be almost as helpful as having access to school staff that understood their child's disability (1: 7). They viewed having somebody they trusted to help them make educational decisions for their children (10: 5) as being more helpful in decision-making than participating in support groups (11: 1), having discussions with professionals outside school (7: 3), knowing about special education laws (3: 2), or understanding of their own legal rights and responsibilities (4: 3). These parents ranked school staff's general attitudes toward the child and family (16: 5) relatively high, but they did not consider teachers' positive attitudes to their family's culture and values (14: 3) to be as helpful. Compared to the other two viewpoints, these parents gave the lowest scores to staff's ability to work together (8: 4) and willingness to include parents as equal members of the team (9: 4).

It's up to us parents. This viewpoint assigned a considerably greater value to parents' internal resources than to external supports offered by professionals and structured socialization. Four parents shared this viewpoint, which had an eigenvalue of 2.23 and explained 15% of the study variance. All were female; two were African-American, and the other two were Caucasian. One parent omitted information about her age; therefore, the average age for this group could not be calculated. Age information provided by the other three parents ranged from mid-forties to late-sixties. The average age of their children was four years and six months. Two children were boys, and two were girls. One child had autism, and three had orthopedic impairments or intellectual disabilities.

Parents embracing this viewpoint considered their understanding of special education law (3: 7), knowledge about services and programs (5: 6), and determination to get what was best for the child (15: 6) to be the most helpful when making educational decisions for their young children with disabilities. Compared to the other two groups, these parents also assigned greater value to their understanding of parental rights and responsibilities (4: 5). They considered external resources involving school staff and other professionals less helpful than internal ones. Of all viewpoints, they credited the lowest value to school staff's positive attitude about the child and family (16: 2), respect for the family culture and values (14: 1), and consideration of parents' dreams and goals for the child (13: 3). Two exceptions to this tendency to favor internal over

external resources were their appreciation of school staff's understanding of special education laws (2: 4) and willingness to include parents as part of the team (9: 4). Although neither resource was described as "most helpful", they received a higher ranking from these parents than from parents who held the other two viewpoints collectively.

It's all about them. This viewpoint emphasized the helpfulness of external resources, specifically those associated with school staff's attitudes and actions to help parents make educational decisions for their young children with disabilities. Three participants (n=3) embraced this viewpoint, which had an eigenvalue of 2.52 and explained 15% of the study variance. One parent was Caucasian, one Latino, and one African-American. Two parents were female, and one was male. Parents' ages averaged at 39 years, and their children's ages averaged at three years and eight months. Two of the children were girls, and one was a boy. One child had autism, and the other two had orthopedic impairment or intellectual disabilities.

Parents who identified with this viewpoint assigned top scores to resources such as having school staff that treated them as equal members of the team (9:7), worked together (8:6), cared about parents' dreams and goals for the child (13:6), had high expectations for the child (12:5), and showed a positive attitude towards the child and family (16:5). They assigned working with school staff that respected the family culture and values (14:4) a greater score than 81% (n=17) of the study sample. They considered their understanding of their child's disability (6:3) and knowledge of special education laws (3:3) to be less helpful in educational decision-making than resources associated with professionals' knowledge, attitudes, and actions. They ranked their determination to get what was best for the child (15:4), understanding of the child's disability and needs (6:3), and knowledge of services or programs (5:4) lower than did parents holding the other two viewpoints.

#### Parents' Commentary and Suggested Resources

Qualitative data gathered from parents upon completion of the Q-sort provided further insights into their views on the helpfulness of these and other resources when making educational decisions for their children. All parents expressed two common sentiments: (a) all selected resources could facilitate parents' decision-making at some point in their journey to secure appropriate education and adequate services for their children and (b) the absence of these resources might delay parents' abilities to make suitable educational decisions for their children with disabilities. Four themes emerged from the added resources suggested by parents.

**Parents' and educators' advocacy skills.** Two parents discussed the importance of parents and teachers developing sound advocacy skills and highlighted the difference between knowing about laws and procedures and advocating for a child with disabilities. One of them spoke specifically about the helpfulness of formal advocacy training in teaching parents how to use what they knew to "make things happen."

Having informal interactions with other parents in the community. A parent of a child with a physical disability highlighted the helpfulness of informal networking and spontaneous interactions with other parents, as opposed to interactions that occurred as part of their participation in parent meetings. She elaborated that through those interactions she had learned about inclusive services and programs and felt more connected to her community.

Having more support from the community. The parent of a child with autism discussed how living in a community that accommodated the needs of all children would empower families to extend the education of their children with disabilities outside the classroom, allowing parents to focus on their long-term educational goals for their children rather than fixing on the "small picture".

Having teachers adequately prepared to teach children with disabilities. Three parents of children with intellectual disabilities (n=2) and autism (n=1) spoke about the need for teachers to be better trained in special methods for teaching young children with disabilities. They emphasized that having professionals who understood and respected the law was helpful only if those professionals also knew how to work with the children.

#### Discussion

In this study, parents' determination to get the services their children need and having school staff who understood the child's disability received the highest rankings for their helpfulness to parents when making educational decisions for their children. However, parents' circumstances seemed to influence their appreciation of specific resources. The age of the child appeared to shape parents' perceptions of the helpfulness of specific resources, with parents of 3-year-olds focusing on informational resources; parents of 4-year-olds relying more on external supports; and parents of 5-year-olds attributing greater value to within-parent resources such as including their own knowledge of educational laws and procedures.

Earlier research indicates that the support needs of families with children with disabilities vary according to numerous issues resulting from changing family dynamics, (Wang & Brown, 2009). Therefore, the variations in parents' views on specific resources noticed in this study may reflect (a) the stage through which parents are going after learning about their child's disability or (b) the changing needs of children with disabilities as they go through various stages of development. Parents of younger children may still be making sense of their children's diagnoses and figuring out how to respond to their new reality. They may view disability information as being more helpful than resources associated with legal aspects of their children's education because understanding their children's condition and needs is their most immediate priority. However, by the time the child is five years of age, parents feel the pressure to consider educational options for their children and may realize the importance of becoming well-versed in special education laws and having a voice in the educational decisions made for their children with disabilities. This may be particularly true for parents who have had enough time to work through their initial reactions to their children's disability diagnoses or whose children have been receiving services for a while.

Previous studies connected educators' limited knowledge of, and compliance with, special education procedures with increased parental stress (Burke & Hodapp, 2014) and ongoing conflict between parents and educators (Lake & Billingsley, 2000; Wagner & Katsiyannis, 2010). Statistical significance of the tendencies observed in this study could not be determined due to the relatively small sample size. Still, the results suggest that parents of older children may have a greater understanding of the importance of having access to educators who are well

informed about the legal workings of the special education system. The difference in parents' views may result from the same process that parents seem to undergo when evaluating the helpfulness of their own knowledge of the legal aspects of special education. Alternatively, this variation may be related to feelings expressed by some parents regarding the importance of having teachers who can adequately teach students with disabilities. As discussed earlier, participants in this study assigned great value to teachers' understanding of disabilities. Therefore, despite seeing the value of working with teachers who are knowledgeable about the special education law, it makes sense that parents' main concerns would be related to teachers' abilities to effectively address children's educational needs. Future research on this subject should include having well-trained teachers as one of the selected resources in order to explore parents' comparative views on the helpfulness of this particular resource when making decisions about their children's education.

During this investigation, parents of children with autism placed a higher value on school staff's understanding of the child's disability than parents of children in the other disability categories. Research has documented the challenges that parents of children with autism face to gain access to professionals qualified to work with their children, and the adverse effects that such challenges have on parents' levels of satisfaction with their children's health and educational services (Montes, Halterman, & Magyar, 2009). Understanding the child's disability was considered a very valuable resource for parents. Having access to school staff who are knowledgeable about autism might seem indispensable for parents to be able to rely on educators to guide them through the decision-making process.

In addition, three distinctive viewpoints on the helpfulness of selected resources in educational decision-making were identified among participants. While the most popular viewpoint considered both internal and external resources to be similarly helpful, the other two viewpoints showed a preference for either within-person resources or external supports provided by professionals, particularly within the educational system. Consistent with results from the descriptive statistics analysis, the group of parents sharing the It's all about them viewpoint had younger children than parents who shared the It's all about us viewpoint, suggesting that parents' perceptions of selected resources may be modified by changes in their children's developmental needs. The different viewpoints identified in this exploration offered objective evidence of what many of us have seen in the field: despite proof of the helpfulness of specific resources, not all parents will judge such resources in the same light. Then, it is unlikely that all parents of young children with disabilities would perceive the value of such resources in the same way that educators and related services professionals do. For this reason, all professionals involved in the care and education of young children with disabilities must regularly monitor parents for changes in their needed support (Alsem et al., 2013). Educators and related services professionals must be prepared to guide parents even when these choose to rely on resources that, at that specific point in time, do not seem to adequately support them in making decisions about their young children with disabilities.

Because the lack of familiarity with Q-methodology (Sexton et al., 1998; van Exel, 2005) may drive readers to judge the relevance of this study's findings through the lens of more traditional methods of inquiry, it is important to emphasize that this study did not seek to provide an all-inclusive inventory of viewpoints held by parents of young children with disabilities. Instead, it

examined the viewpoints that parents within a demarcated group had on the relative helpfulness of selected resources when making educational decisions for their young children with disabilities. By adding to the current body of knowledge on parents' perceptions and viewpoints on the relative helpfulness of the selected resources, this study contributed to our understanding of the different ways in which parents of children with disabilities may approach educational decision-making and construe the helpfulness of various strategies and supports during that process. That five (n=5) out of the 21 parents participating in the study did not conform with any of the identified viewpoints suggests that additional viewpoints on the subject may exist. Future studies should include larger and more diverse samples, to explore this assumption.

In the past, parents of younger children have attributed less significance to using support groups than parents of older children (i.e., children placed in upper grades) with disabilities (Mandell & Salzer, 2007). Still, in this study, participants' lower rankings of their involvement with support groups -irrespective of the children's age or disabilities- was an unexpected finding due to the relationship that all participants had with local disability advocacy agencies and support groups. This finding, combined with one participants' comment regarding the greater value of informal interactions with other parents over interactions occurring within structured meetings, suggests that parents of young children with disabilities may view support groups as a source of emotional nourishment rather than a source of guidance about the educational decisions they must make for their children.

Lastly, family cultural perspectives and life experiences are known to influence both parents' relationships with the educational system and responses to educators' expectations of the role of parents and school in the education of children with disabilities (Olivos, 2009). The limited emphasis that participants placed on the helpfulness of having school staff who understood their family culture and values might reflect the fact that most participants were Caucasian and, therefore, less likely to be affected by any potential deficit in cultural competence on the part of the educators.

#### Conclusion

Although participants in this study agreed that each of the selected resources would be helpful in their journey to secure adequate education and services for their children with disabilities, parents' determination to get what was best for the children, and parents' and teachers' understanding of the children's disabilities, obtained the highest scores as being helpful to parents when making educational decisions. Parents' views on the helpfulness of specific resources appears to be influenced by their children's ages and types of disabilities. Viewpoints on the helpfulness of selected resources varied among parents. Although most parents found it helpful to use a balanced combination of internal and external resources, other parents showed more polarized views and a tendency to favor mostly internal or mostly external resources when making educational decisions for their children with disabilities.

This study is unique because it provides a framework for understanding how parents' perceptions of the relative helpfulness of resources identified through decades of research fit within distinctive viewpoints of what helps them the most when making educational decisions for their children with disabilities. Likewise, this study serves as a stepping stone for future research on the resources that individual parents may be more likely to utilize at different points in their

children's educational decision-making process. Findings from this exploration remind us of the importance of (a) avoiding one-size-fits-all approaches to supporting parents of children with disabilities and (b) providing professionals involved in the education and care of young children with disabilities with a better understanding of different viewpoints about the helpfulness of resources that individual parents may hold, and their likelihood to rely on specific resources.

## References

- Ainbinder, J. G., Blanchard, L. W., Singer, G. H. S., Sullivan, M. E., Powers, L. K., Marquis, J. G., & Santelli, B. (1998). A qualitative study of parent to parent support for parents of children with special needs. *Journal of Pediatric Psychology*, 23 (2), 99-109.
- Alsem, M. W., Siebes, R. C., Gorter, J. W., Jongmans, M. J., Nijhuis, B. G. J., & Ketelar, M. (2013). Assessment of family needs in children with physical disabilities: Development of a family needs inventory. *Child: Care, Health and Development, 40* (4), 498-506. DOI: 10.1111/cch.12093.
- Ayvazoglu, N. R., Oh, H., & Kozub, F. H. (2006). Explaining physical activity in children with visual impairments: A family systems approach. *Exceptional Children*, 72, 235-248.
- Bailey, D. B., Hebbeler, K., Scarborough, A., Spiker, D., & Mallik, S. (2004). First experiences with early intervention: A national perspective. *Pediatrics*, 113 (4), 887-896.
- Bakermans-Kranenburg, M. J., van IJzendoorn, M. H., Bokhorst, C. L., & Schuengel, C. (2004). The importance of shared environment in infant-father attachment: A behavioral genetic study of the attachment Q-sort. *Journal of Family Psychology*, 18, 545-549.
- Breitkreutz, R., Wunderli, L., Savage, A., & McConnell, D. (2014). Rethinking resilience in families of children with disabilities: A sociological approach. *Community, Work & Family, 17* (3), 346-365. Retrieved from http://dx.doi.org/10.1080/13668803.2014.893238
- Brown, S. R. (1980). *Political subjectivity: Applications of Q methodology in political science*. New Haven, CT: Yale University Press.
- Brown, J. D., Moraes, S., & Mayhew, J. (2005). Service needs of foster families with children who have disabilities. *Journal of Child and Family Studies*, 14 (3), 417-429.
- Burke, M. M., & Hodapp, R. M. (2014). Relating stress of mothers of children with developmental disabilities to family-school partnerships. *Intellectual and Developmental Disabilities*, 52 (1), 13-23. DOI: 10.1352/1934-9556-52.1.13.
- Caldera, Y. M. & Lindsey, E. W. (2006). Coparenting, mother-infant interaction, and infant parent attachment relationships in two-parent families. *Journal of Family Psychology*, 20, 275-283.
- Coogan, J., & Herrington, N. (2011). Q methodology: An overview. *Research in Secondary Teacher Education*, 1 (2), 24-28.
- Creswell, J. W., & Poth, C. N. (2017). *Qualitative Inquiry & Research Design: Choosing from Five Approaches* (4th Ed.). Thousand Oaks, California: Sage Publications, Inc.
- Fish, W. (2008). The IEP meeting: Perceptions of parents of students who receive special education services. *Preventing School Failure*, 53 (1), 8-14.
- Freedman, R. I. & Boyer, N. C. (2000). The power to choose: Supports for families caring for individuals with developmental disabilities. *Health and Social Work*, 25, 1-10. ISSN: 0360-7283.
- Gane, L. W., Iosif, A. M., Flynn-Wilson, L., Venturino, M., Hagerman, R. J., Seritan, A. L.

- (2010). Assessment of patient and caregiver needs in fragile x-associated tremor/ataxia syndrome by utilizing Q-sort methodology. *Aging and Mental Health*, *14*, 1000-1007.
- Garwik, A. W., Patterson, J. M., Bennett, F. C., Blum, R. W. (1998). Parents' perceptions of helpful vs. unhelpful types of support in managing the care of preadolescents with chronic conditions. *Archives of Pediatric and Adolescent Medicine*, 152, 665-671.
- Granger, S., des Rivieres-Pigeon, C., Sabourin, G., & Forget, J. (2010). Mothers' reports of their involvement in early intensive behavioral intervention. *Topics in Early Childhood Special Education*, 20 (10), 1-10. DOI: 10.1177/0271121410393285. Retrieved from http://tecse.sagepub.com
- Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. *Journal of Developmental and Physical Disabilities*, 14, 159-171.
- Hess, R. S., Molina, A. M., & Kozleski, E. B. (2006). Until somebody hears me: parent voice and advocacy in special educational decision making. *British Journal of Special Education*, 33 (3), 148-157.
- Hiebert-Murphy, D., Trute, B., & Wright, A. (2011). Parents' definition of effective child disability support services: Implications for implementing family-centered practice. *Journal of Family Social Work, 14*, 144-158. ISSN: 1052-2158. DOI: 10.1080/10522158.2011.552404
- Hughes, M. T., Valle-Riestra, D. M., & Arguelles, M. E. (2008). The voices of Latino families raising children with special needs. *Journal of Latinos and Education*, 7 (3), 241-257.
- Individuals with Disabilities Education Act Amendments of 1997, 20 U.S.C. 1400. Retrieved from http://www2.ed.gov/policy/speced/leg/idea/idea.pdf
- Individuals with Disabilities Education Improvement Act of 2004, 20 U.S.C. 1400 et seq. Retrieved from http://idea.ed.gov/
- Ingber, S., Al-Yagon, M., & Dromi, E. (2010). Mothers' involvement in early intervention for children with hearing loss: The role of maternal characteristics and context-based perceptions. *Journal of Early Intervention*, 32 (5), 351-369.
- Kalyanpur, M., Harry, B., & Skrtic, T. (2000). Equity and advocacy expectations of culturally diverse families' participation in special education. *International Journal of Disability, Development and Education, 17* (2), 119-136.
- Lake, J. F. & Billingsley, B. S. (2000). An analysis of factors that contribute to parent-school conflict in special education. *Remedial and Special Education*, 21 (4), 240-251.
- Litt, J. S. & McCormick, M. C. (2015). Care coordination, the family-centered medical home, and functional disability among children with special health care needs. *Academic Pediatrics*, 15 (2), 185-190.
- Mandell, D. S. & Salzer, M. S. (2007). Who joins support groups among parents of children with autism? *Autism*, 11, 111-122.
- McDonnall, M. C., Cavenaugh, B., S., & Giesen, J. M. (2010). The relationship between parental involvement and mathematics achievement for students with visual impairments. *The Journal of Special Education*, 20 (10), 1-12. DOI: 10.1177/0022466910365169. Retrieved from http://journalof specialeducation.sagepub.com
- McKeown, B. & Thomas, D. (1988). Q methodology. Newbury Park, CA: Sage Publications.
- Miedel, W. T., & Reynolds, A. J. (2000). Parent involvement in early intervention for disadvantaged children: Does it matter? *Journal of School Psychology*, *37* (4), 379-402.
- Montes, G., Halterman, J. S., & Magyar, C. I. (2009). Access to and satisfaction with school and community health services for US children with ASD. *Pediatrics*, 124, 407-413.

- Olivos, E. M. (2009). Collaboration with Latino families: A critical perspective of home-school interactions. *Intervention and School and Clinic*, 45 (2), 109-115.
- Olmsted, M.G., Bailey, D.B., Raspa, M., Nelson, R.E., Robinson, N. D., Simpson, M.E. & Guillen, C. (2010). Outcomes reported by Spanish-speaking families in early intervention. *Topics in Early Childhood Special Education*, 20 (10), 1-11.
- Rahi, J. S., Manaras, I., Tuomainen, H., & Hundt, G. L. (2004). Meeting the needs of parents around the time of diagnosis of disability among their children: Evaluation of a novel program for information, support, and liaison by key workers. *Pediatrics*, *114*, 477-482. DOI: 10.1542/peds.2004-0240
- Roberts, W. L. (1986). Nonlinear models of development: An example from the socialization o competence. *Child Development*, *57*, 1166-1178.
- Sexton, D., Snyder, P., Wadsworth, D., Jardine, A., & Earnest, J. (1998). Applying Q methodology to investigations of subjective judgments of early intervention effectiveness. *Topics in Early Childhood Special Education*, 18, 95-122.
- Sheppard, M. E. & Vitalone-Raccaro, N. (2016). How physicians support children with disabilities and their families: Roles, responsibilities and collaborative partnerships. *Disability and Health Journal*, *9*, 692-704.
- Sloper, P., Greco, V., & Beecham, J., & Webb, R. (2006). Key worker services for disabled children: What characteristics of services lead to better outcomes for children and families? *Child: Care, Health & Development, 32* (2), 147-157.
- Spann, S. J., Kohler, F. W., & Soenksen, D. (2003). Examining parents' involvement in and perceptions of special education services: An interview with families in a parent support group. *Focus on Autism and Other Developmental Disabilities*, 18 (4), 228-237.
- Stephenson, W. (1953). *The study of behavior: Q-technique and its methodology*. Chicago, IL: University of Chicago Press.
- Stanley-Gane, L., Flynn, L., Neitzel, K., Cronister, A., & Hagerman, R. J. (1996). Expanding the role of the genetic counselor. *American Journal of Medical Genetics*, 64 (2), 382-387.
- Tetreault, S., Blais-Michaud, S., Deschenes, P. M., Beaupre, P., Gascon, H., Boucher, N., & Carriere, M. (2012). How to support families of children with disabilities? An exploratory study of social support services. Child & Family Social Work, 19, 272-281. DOI: 10.1111/j.1365-2012. 00898.x
- Tractinsky, N., & Jarvenpaa, S. L. (1995). Information systems design decisions in a globa versus domestic context. *Management Information Quarterly*, 19 (4), 507-534.
- Trainor, A. A. (2010a). Reexamining the promise of parent participation in special education: An analysis of cultural and social capital. *Anthropology & Education Quarterly*, 44 (3), 245-263.
- Trainor, A. A. (2010b). Diverse approaches to parent advocacy during special education home school interactions: Identification and use of cultural and social capital. *Remedial and Special Education*, 31 (1), 34-47.
- van Exel, J. (2005). *Q methodology: A sneak preview*. Retrieved from <a href="http://qmethod.org/articles/vanExel.pdf">http://qmethod.org/articles/vanExel.pdf</a>
- Vanegas, S. B., & Abdelrahim, R. (2016). Characterizing the systems of support for families of children with disabilities: A review of the literature. *Journal of Family Social Work*, 19 (4), 286-327. Retrieved from http://dx.doi:org/10.1080/10522158.2016.1218399

- Wagner, J. Y., & Katsiyannis, A. (2010). Special Education litigation update: Implication for school administrators. *NASSP Bulletin*, 94 (1), 40-52.
- Wang, M., & Brown, R. (2009). Family quality of life: A framework for policy and social service provisions to support families of children with disabilities. *Journal of Family Social Work*, 12, 144-167. DOI: 10.1080/10522150902874842.
- Watts, S., & Stenner, P. (2012). *Doing Q methodological research: Theory, method, an interpretation.* Thousand Oaks, CA: Sage Publications Inc.
- White, N. & Hastings, R. P. (2004). Social and professional support for parents of adolescents with severe intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 17 (3), 181-190.
- Zionts, L. T., Zionts, P., Harrison, S., & Bellinger, O. (2003). Urban African-American families' perceptions of cultural sensitivity within the special education system. *Focus on Autism and Developmental Disabilities*, 18, 41-50.

#### About the Authors

María Isolina Ruiz, Ph.D. is an assistant professor of special education at the University of Louisiana at Lafayette. Her research focuses on parents' participation in the processes associated with the education of their children with special needs; school collaboration with culturally and linguistically diverse families; effective assessment and instruction of diverse students, including English; and the development of responsive pre-service and inservice teachers.

**Linda Flynn, Ph.D.** is a professor at the University of New Orleans. Her areas of research include services and supports for families of children with disabilities, supporting children with disabilities in inclusive settings, and priorities of culturally and linguistically diverse children and their families. She has served as visiting professor at the University of Vienna and has served as Co-Director of the International Symposium between the University of New Orleans and the University of Innsbruck.

**Lauren K. Giovingo, Ph.D.** served as the LEND coordinator, ASD Interdisciplinary Clinic coordinator, and an educational consultant for the Human Development Center at the Louisiana State University Health Sciences Center-New Orleans at the time this study was completed. Her teaching, training, and research interests include interdisciplinary collaboration, early identification of autism spectrum disorders, academic and behavioral strategies and interventions, and data-based decision making to improve student outcomes.

**Philip G. Wilson, Ph.D.** is an associate professor in the School of Allied Health Professions and director of the Human Development Center at the Louisiana State University Health Sciences Center-New Orleans. His teaching and research interests include promoting and supporting the full participation of individuals with disabilities and their families in all aspects of community life.