español | Chinese

ECRP
Early Childhood Research & Practice

Lilian G. Katz
Editor

Jean Mendoza
Susan Fowler
Associate Editors

Kevin Dolan
Managing Editor

Established
February 27, 1999
ISSN 1524-5039

...a peer-reviewed multilingual journal on the development, care, and education of young children

Current Issue: Volume 15 Number 1
Past Issues
Beyond This Issue
Search ECRP

Sign up for the **Email Newsletter**

Find us on Facebook

About ECRP
Sponsoring ECRP
Information for Authors
ECRP Survey

Send comments to the ECRP Editor.

Like

Home | Journal Contents | Issue Contents

Mirar esta página en español

Share

Volume 15 Number 1

Early Intervention Experiences of Families of Children with an Autism Spectrum Disorder: A Qualitative Pilot Study

Christan Grygas Coogle
West Virginia University

Amy R. Guerette & Mary Frances Hanline
Florida State University

Abstract

The purpose of this study was to obtain an understanding of the unique experiences of families who have a young child at risk for or identified with an autism spectrum disorder and their experiences with early intervention. Thirty-nine parents of children with or at risk for an autism spectrum disorder receiving Part C services in a state in the southeastern United States participated in the study. Responses to four open-ended questions regarding experiences with early intervention were analyzed using qualitative research methodology. Results suggested that families have different experiences related to their participation in services and interactions with service providers, as well as varying feelings about services. Implications for service providers are discussed in relation to recognizing the importance of family participation, matching services to the needs of the family, and incorporating interpersonal skills into early intervention practice with families of young children with autism spectrum disorder.

Introduction

Early intervention services in the United States were established in 1986 as part of the Individuals with Disabilities Education Act (IDEA) in recognition of "an urgent and substantial need" to enhance the development of infants and toddlers with disabilities, decrease educational expenses by minimizing the need for special education, diminish the likelihood of institutionalization, enhance the capacity of families to meet their children's needs, and expand possibilities for independent living (U.S. Department of Education, 2004). In 2011, 343,000 infants and toddlers in the United States received early intervention (EI) services in accordance with Part C of the reauthorized IDEA of 2004 (Lazara, Danaher, & Goode, 2012). Each state determines authorization requirements regarding what agencies provide EI services and how eligibility for services is determined.

Research indicates that early intervention has strong potential to improve children's quality of life by enhancing development and preventing additional developmental delays and/or disabling conditions (Barnett, 1995; Gwynne, Blick, & Duffy, 2009; Guralnick, 1997; Talay-Ongan, 2001; Yoshikawa, 1995). Studies indicate that EI is most likely to be effective when it is based on family priorities and occurs within the context of everyday family routines and activities (Bruder, 2000; Dunst, 2000; Farrell, 2009; Talay-Ongan, 2001). Part C of IDEA requires the provision of family-centered services; basic principles of family-centeredness include building on family strengths, providing family choice regarding all aspects of EI services, and engaging in family-professional collaboration (Bruder, 2000; Crais, Roy, & Free, 2006; Dunst, Hamby, & Brookfield, 2007; Jung & McWilliam, 2005; Trivette & Dunst, 2005; A. Turnbull et al., 2007).

Families of young children with a variety of disabilities have reported positive experiences with family-centered

EI services, including delivery of services in the home, family involvement in the EI process, and social supports and resources that met family needs. In several studies, families have indicated preference for nonjudgmental, sincere, caring, creative, supportive, and responsive EI service providers (e.g., Applequist & Bailey, 2000; Bailey, Scarborough, & Hebbeler, 2003; Hurtubise & Carpenter, 2011; Jackson, Traub, & A. Turnbull, 2008; Wade, Mildon, & Matthews, 2007). Families have also reported that positive child outcomes from EI and the personal skills of service providers enhance the family's quality of life and family members' relationships with their child (Epley, Summers, & A. Turnbull, 2011).

Other studies have reported families' dissatisfaction with aspects of EI service delivery, such as lack of opportunities for involvement in the process and a desire to be more involved (Applequist & Bailey, 2000), and a need for more information and/or a better understanding of information shared by professionals (Hurtubise & Carpenter, 2011; Jackel, Wilson, & Hartmann, 2010; Lovett & Haring, 2003; Otero-Fernandez, 2004; Shannon, 2004; Wilcox, Dugan, Campbell, & Guimond, 2006). Families have reported uncertainty regarding their role in the development of the Individual Family Service Plan (IFSP), dissatisfaction with the absence of social supports and service options (Jackson et al., 2008), and frustration with the length of wait-time for receiving services (Bailey et al., 2003; Bailey, Hebbeler, Scarborough, Spiker, & Mallik, 2004; Haring & Lovett, 2001; Otero-Fernandez, 2004; Shannon, 2004; Wade et al., 2007).

Of special significance to this study are families with young children at risk for an autism spectrum disorder (ASD). Baio (2012) defines ASDs as "…a group of developmental disabilities characterized by impairments in social interaction and communication and by restricted, repetitive, and stereotyped patterns of behavior." Children are qualifying for EI services after being diagnosed with ASD at young ages with increasing frequency (Henderson, 2009), but there is limited research investigating EI experiences from the unique perspectives of families who have young children at risk for or identified with ASD. The available research has reported family experiences with and perspectives on EI services similar to those of families of children with disabilities other than ASD. Parents of young children with ASD reported that they value being involved in decision-making, having access to resources, receiving services in the home, allowing for flexibility in services, and utilizing a team approach (Beals, 2004; Patterson & Smith, 2011; A. Webster, Feiler, V. Webster, & Lovell, 2004). Parents have reported valuing opportunities to establish social networks and relationships with other families of young children with ASD (Grindle, Kovshoff, Hastings, & Remington, 2009) and to learn new intervention strategies that could improve the child's communication, play, and social skills (Grindle et al., 2009; Patterson & Smith, 2011; A. Webster et al., 2004). Improved family interactions, including sibling relationships, have also been reported as benefits of EI (Grindle et al., 2009).

Studies have also found that families of young children with ASD also identify negative experiences with their children's EI services. Concerns have included cost of service delivery as well as wait time between EI referral and EI assessment and between determination of eligibility and service delivery (Grindle et al., 2009; A. Webster et al., 2004). Parents sometimes reported frustration with the lack of consistency among professionals when determining the most effective intervention approach and with service providers who seemed inflexible, unorganized, unknowledgeable, unreliable, and unresponsive to individual families' informational, support, and emotional needs (Grindle et al., 2009; Patterson & Smith, 2011; Rodger, Keen, Braithwaite, & Cook, 2008; A. Webster et al., 2004). Families reported desiring services that resulted in explicit, practical, individualized, and child-friendly interventions based on identified learning goals for the child. When EI services were delivered in an unsupportive, non-individualized manner, families reported negative experiences with interventions that felt invasive and disruptive, that increased family stress, and that led them to feel overwhelmed, isolated, and incapable of providing intervention (Beals, 2004; Grindle et al., 2009; Patterson & Smith, 2011; Rodger et al., 2008; A. Webster et al., 2004).

The research on the perceptions of families of young children with ASD regarding EI services has included only a single family case study (Beals, 2004) and four evaluations of specific programs: Applied Behavior Analysis (ABA) (Grindle et al., 2009), More than Words (Patterson & Smith, 2011), Early Intensive Intervention Program (A. Webster et al., 2004), and The Stronger Families Program (Rodger et al., 2008). Because the number of children under the age of 3 years with ASD is increasing (Henderson, 2009), an understanding of the needs of these families is of critical importance.

The purpose of this pilot study was to obtain a more thorough understanding of families' experiences by including parents from a broader segment of the population of parents of young children with ASD. Research questions guiding the collection and analysis of data were:

- In what activities do parents report engaging during EI sessions?
- In what activities do parents report service providers engaging in during EI sessions?
- What do parents report as positive qualities of EI services received?
- What aspects of EI service provision do parents report as needing to be changed?

Method

Participants

Thirty-nine parents with a child between the ages of birth and 3 years who was identified as having or being at risk for ASD participated in the study. All families lived in the state and received EI services through the state's early intervention agency (hereafter referred to as EIA), the state's Part C provider. Limited demographic information was collected so that confidentiality could be ensured. Twenty-four of the 39 children were diagnosed with ASD, and 15 were considered to be "at risk" for ASD. Twenty-eight families reported receiving services from multiple providers. Eleven received services from one provider. Twenty-one participants reported receiving services in both the home and community. One reported receiving services only in the home; 3, in a clinic; 2, in a child care setting; 1, at the EIA office; 8, in a variety of settings, and 3, other unspecified settings.

Instrument

A survey developed previously for families with young children with hearing impairments (Harrison, Dannhardt, & Roush, 1996) was modified for use with this population. The survey consisted of questions about the child, the child's intervention program, and IFSP development. It included questions with five-point Likert scale responses, yes/no response questions, and four open-ended questions. The adapted survey was piloted with three families known to the first author who had young children with disabilities; two questions were subsequently modified based on feedback from these families.

For this study, only responses to the four open-ended questions were analyzed. Open-ended questions are typically used in exploratory/pilot research, allowing respondents to include more information in their responses about feelings and attitudes most important to them (Groves et al., 2009). The open-ended survey questions used in this study were:

- Describe what you and/or your family do during intervention.
- Describe what the service provider does during intervention.
- What do you like about receiving services under the EIA program?
- What would you like to change about receiving services under the EIA program?

Procedure

Recruitment. Participants were recruited from the state's seven regional autism and related disabilities centers. These centers invited eligible families to participate in the study through their Listserv by posting the Web address to complete the survey in an e-newsletter, and/or emailing information about the study. Parents who volunteered to participate then responded anonymously to the survey questions online. Overall response rate could not be calculated because it was impossible to determine how many individuals received and opened the e-newsletter that included the recruitment letter.

Data Collection and Analysis. Qualitative methods were used to analyze parental responses to the four open-ended survey questions. Credibility of the data, as discussed by Brantlinger et al. (2005), was established through investigator triangulation, researcher reflexivity, maintenance of an audit trail, purposive sampling, code-recode strategy, thick description, and particularizability.

The first author downloaded participant responses from the online survey tool into an Excel© spreadsheet. Excel© was used throughout the analysis process to organize data. An initial reading of responses was conducted. Analysis entailed multiple iterations of the data for the research questions. However, the iteration process for research questions 1 and 2 differed from the analysis for research questions 3 and 4; a decision was made to analyze responses to research questions 3 and 4 together, because participants frequently referred to likes and dislikes about services in their responses to either question. Results for those two questions will thus be discussed under research question 3.

Research Questions

Research Questions 1 and 2. The first author sorted participant responses into units of meaning—codes developed to reference descriptive or inferential information collected (Miles & Huberman, 1994). Themes were developed by means of pattern coding, which "chunks" meaning units to form themes or subthemes (Miles & Huberman, 1994). The first and second author met to determine reliability, obtaining 96.61% agreement on question 1 and 100% agreement on question 2. Disagreements were resolved through discussion.

Research Question 3. As indicated above, responses to research questions 3 and 4 were ultimately combined, as participants tended to combine discussion of positive and negative experiences in response to either question. Themes were identified as for questions 1 and 2. Subthemes were also identified using pattern coding. The second author responded to the first author's coding patterns; agreement was 94.50% for this research question. Disagreements were resolved through discussion.

Results

After empirical materials were coded and reliability conducted, the three authors agreed on titles of the themes and subthemes. The themes and subthemes are addressed in detail in discussion of each research question below. Also see Table 1.

In what activities do parents report engaging during EI sessions?

Thirty-four participants indicated ways that they participated in EI sessions; five participants gave off-topic responses. Five themes were identified: (1) facilitating child development, (2) sharing information with service providers, (3) observing their child and service provider, (4) learning new skills, and (5) participating minimally. The specific ways parents reported participating in EI sessions varied but were not dependent on the service delivery setting or the discipline of the service provider.

Theme 1: Facilitating Child Development. Fifteen parents (29% of responses relevant to research question 1) described intervention as a time when they were "facilitating child development" by interacting with the child. Parents specifically indicated working toward child goals related to communication, interactive play, eye gaze, and behavior. Other parents mentioned how they supported their child during EI (e.g., *"I work with him, by helping him move his hands and show him how things are done and reward him.")*

Many parents referred to specific intervention techniques they used to promote child development, such as helping the child complete tasks, engaging in play with the child, and utilizing specific models such as The Greenspan Floortime Approach ™ (Wieder & Greenspan, 2003). For example, one parent described using several different strategies (e.g., *"We do floor time mostly with both therapies. We work on getting our son to communicate with us, as well as have some sort of interactive play and eye contact.")*

Theme 2: Sharing Information with Service Providers. Twelve participants (25% of responses relevant to research question 1) reported engaging in EI sessions by "sharing information with service providers." "Sharing information" included updating the EI provider on the child's progress or informing the provider about family concerns, listening to the service provider, asking questions, and providing explanations. For example, one parent reported describing for the provider techniques that have worked well for them when managing challenging behaviors: *"[I] explain reason for my child's behavior and other ways I have found effective in helping him."*

Theme 3: Observing the Child and Service Provider. Ten parents (19% of parent statements relevant to research question 1) reported observing the interventionist work with their child during intervention sessions; for some parents, this was their sole reported activity during sessions.

Theme 4: Learning New Skills. Eight parents (15% of responses relevant to research question 1) indicated learning new skills and instructional strategies to enhance their child's development during EI sessions. One parent, for example, stated that the whole family is present for EI so that they can learn communication techniques: *"Myself, my husband, as well as my mother, are present for as many therapy sessions as possible; and it is very important that we are taught how to communicate functionally with our daughter."* One parent reported taking notes during EI sessions to help remember the techniques learned.

Theme 5: Participating Minimally. Six parents (12% of responses relevant to question 1) indicated minimal participation during intervention sessions. Four of the six were receiving services in the home. Parents either said that they "do nothing" during intervention or reported being in a separate location (e.g., *"During intervention, we have to leave them alone. But after intervention, my service provider tells me everything and gives me clues and strategies to work with my kid!"*). This parent indicated that her child's needs were being met despite separation during EI sessions.

In what activities do parents report that the service provider engages during intervention?

All 39 participants explained how the service provider engages during intervention. The three themes identified suggest that service providers' activities during EI sessions mirrored the ways parents reported being involved. That is, respondents perceived service providers as facilitating child development, sharing information, and developing new family skills. Respondents' descriptions of EI service providers' activities during intervention did not vary across providers' disciplines or service delivery setting.

Theme 1: Facilitating Child Development. Twenty-eight participants (67% of statements relevant to research question 2) identified service provider engagement in intervention sessions as being focused on facilitating child development. Participants noted specific strategies and approaches EI service providers used to facilitate children's development toward such goals as using sign language, engaging in appropriate social interactions, and increasing receptive and expressive language. Parents referred to service providers' use of play-based intervention and Greenspan's Floortime Model™ (Wieder & Greenspan, 2003). Some parents gave general responses (e.g., *"She interacts with my son."*), while others were specific about service providers' activities: *"(1) speech therapist—uses toys and daily activity as motivation for speech. (2) behavioral therapist - potty training (3) early interventionists—teach occupational and speech skills using toys.")*

Theme 2: Sharing Information. Eight parents (19% of responses relevant to research question 2) indicated the

EI provider engaged in "sharing information," which they further described as asking and/or answering questions and/or answered questions and made suggestions. One parent explained how the provider communicated and collaborated: *"Our service provider always calls me to set up an appointment and when we meet up we just go over everything that has happened to my son. We bring the entire therapist team together to go over what they have seen or where we can improve. If I have any questions she always answers them. We sometimes bump into each other at different events and she is always concerned about our family."*

Theme 3: Developing New Family Skills. Six parents (14% of statements relevant to research question 2) reported that service providers participated in EI sessions by helping the family develop new understanding and skills, including knowledge of strategies to use with the child. One parent explained that the provider taught the family what to do and what not to do. Another commented, *"They have got him to sign since he's not speaking yet, and eat some new foods. Also they have taught my family and I helpful techniques to use when they are not present."*

What do parents report as positive qualities of EI services, and what aspects of EI service provision do parents report as needing to be changed?

All 39 participants mentioned positive qualities of EI and/or aspects they feel needed to change. The two themes emerged in responses to this question were coded as (1) positive qualities and (2) changes needed. The majority of comments were related to positive qualities. Seven parents said that they would not change any aspect of services, indicating that they were completely satisfied with their EI services. Parents who reported that they would not change anything received services from providers of varying disciplines and with diverse service delivery settings.

Theme 1: Positive Qualities. Thirty-eight participants indicated positive qualities of EI services; one participant indicated perceiving nothing positive about EI services. "Positive qualities" were coded into four subthemes:

- access to resources,
- personal characteristics of service providers,
- opportunities for new skill development, and
- convenience of services to the family.

No relationship was evident between positive qualities of EI and service delivery setting or discipline.

Access to resources. Twenty-seven parents (26% of statements relevant to theme 1 of research question 3) identified access to an array of services and resources as a positive aspect of EI. Services and supports identified included child evaluations, therapies (i.e., physical therapy, occupational therapy, or speech therapy), and access to information (i.e., classes related to child development, information regarding transition). One participant explained how EI providers provided step-by-step suggestions: The EIA program *"evaluates and then gives you direction. They don't expect you to figure it all out on your own, which is nice for parents who have never experienced a child with developmental disabilities. Other than that, they have met my requests and concerns in a timely fashion and are compassionate and considerate when doing so."*

Personal characteristics of service providers. Seventeen parents (17% of responses relevant to question 3) indicated that characteristics of service providers were a positive quality of EI. Specific provider characteristics identified included wanting the child to succeed, being liked by the child, and being caring, easy to work with, helpful, organized, understanding, professional, personable, trustworthy, and friendly. One parent expressed appreciation for service providers' level of concern for the child: *"The therapists we have now truly care for our child and rally behind him as much as we do."*

Opportunities for new skill development. Ten parents (10% of responses relevant to research question 3) identified the opportunity to learn new skills to promote their child's development as a positive quality of EI. Specific skills included having a better understanding of the child and learning strategies to use to work with the child. One parent commented that she knew more about her child because of EI services: *"If it wasn't for [the EIA program] I would not be as educated about my son as I am today."*

Convenience of services to the family. Ten participants (10% of statements relevant to research question 3) identified the convenience of location and timing of services as positive qualities of EI. Seven of those 10 respondents reported liking services in their home because the child felt more comfortable and they found it easier to duplicate the providers' strategies; some referred to difficulty taking their children out of the home because of behavioral challenges. Three participants reported receiving services in other locations (e.g., a clinic, EIA office, and a child care program providing services to young children with disabilities). Participants also referred to conveniently scheduled visits; one commented, *"I love that all the therapists can work out a great schedule based on my son's schedule and they complete all services at my home so I do not have to travel and he feels more comfortable in his own environment."*

Theme 2: Changes Needed. Thirty-two participants reported aspects of their EI experience that they would wish to change; 7 participants indicated that they would not change anything. Two subthemes emerged from parents' descriptions of negative experiences and suggestions for change:

- *Dissatisfaction with services.* Twenty-four parents (24% of total responses relevant to research question 3) indicated dissatisfaction with services, referring to wait time before receiving services, an inconvenient schedule and location for services, and ineffective intervention. For example, one parent stated, *"His speech therapy isn't as effective. It's very structured and intimidates him."* Other responses suggested too few services, inability to extend services through preschool, lack of funding, and the need for more services such as specialized intervention, transition support, follow up, training for families, and explanation of intervention practices (e.g., "*I am not sure what they do besides feed my son."*). One comment exemplified overall dissatisfaction with services: "*The wait to get into the hospital rehabilitation center was a three-four month wait. Also, our service provider could not understand, that we would not change our entire schedule for 2.5 hours of therapy per week because and the services were over an hour away from our home, and no one calculated, traffic, nap time and feeding for a child with a severe development delay…the services we received from [the EIA program] would not even make a difference in our EIs. The services that we were provided was not enough, we have funded our EI ourselves in hopes for a best outcome for our child."*
- *Dissatisfaction with service providers.* Fourteen participants (13% of responses relevant to research question 3) expressed dissatisfaction with service providers. These responses expressed desire for therapists to be "better," to be more effective communicators, and to take family concerns more seriously. One participant commented,"*I would like a more experienced service coordinator, one who doesn't seem to be too inundated to help, one who is more than just polite, one who really knows what she is doing, one who returns phone calls, one who really seems to care, and especially one who does not have me waste precious time on getting my child the therapy and care she needs and deserves.*"

One respondent saw the provider's lack of punctuality as a negative experience because it decreased the amount of time the service provider spent with the child: "*Show up 30 to 60 minutes late on many occasions. Hurries through the exercises because there is not enough time to explain what she is doing."*

Some parents referred specifically to a service provider's interaction with the family. One parent commented, *"The speech therapist we fired referred to herself as being like super nanny. Long story short, took a toy from my son, made him cry, then did a restraint on him, told my husband to point his finger in my son's face and tell him no. I had to intervene."* Another wrote, *"The first speech therapist we had came into the home and played frantically with Mikey, but had no goals in mind and jabbered at me about how nothing was wrong with him."*

Table 1
Number and percent of responses per theme and subtheme within each research question

Research Question 1
In what activities do parents report engaging during intervention sessions? (26% of total responses coded)

Themes (N = 34 families)	Number	% within theme
Facilitating child development	15	29
Sharing information with service provider	12	25
Observing their child and service provider	10	19
Learning new skills	8	15
Participating minimally	6	12
Total Responses	51	

Research Question 2
In what activities do parents report the service provider engages during intervention? (21% of total responses coded)

Themes (N = 39 families)	Number	% within theme
Facilitating child development	28	67
Sharing information	8	19
Developing new family skills	6	14
Total Responses	42	

Research Question 3
What do parents report as positive qualities of EI services, and what aspects of EI service provision do families report as needing to be changed? (53% of total responses coded)

Themes and Subthemes		Number	% within theme/subtheme
Theme: Positive Qualities (N = 38 families)		64	63
Subthemes:	Access to resources	27	26

	Personal characteristics of service providers	17	17
	Opportunities for new skill development	10	10
	Convenience of services to the family	10	10
Theme: Changes needed (N = 32 families)		38	37
Subthemes:	Dissatisfaction with services	24	24
	Dissatisfaction with service providers	14	13

Discussion

Results of this pilot study indicate that families of children with or at risk for ASD reported varied experiences with and perceptions of their EI services.

Consistent with findings from other studies of families of young children with ASD (i.e., Beals, 2004; Grindle et al., 2009; Patterson & Smith, 2011; Rodger et al., 2008; A. Webster et al., 2004; Trudgeon & Carr, 2007), parents in this study expressed appreciation for supportive relationships with service providers, flexible and convenient services that met family needs, and interventions that resulted in positive changes for their children. They identified strengths of EI that included access to information to help them better understand their children and facilitate their children's development, and access to relevant community resources and services. Participants indicated that they valued opportunities to collaborate with EI service providers to learn new skills and help their children. They also appreciated teaming with professionals who were well organized and knowledgeable, who demonstrated commitment to the child and family, and who were personable and friendly. These findings are similar to those in studies involving parents of children with other disabilities (e.g., Jackson et al., 2008; Jackel, Wilson, & Hartmann, 2010).

Parents expressed dissatisfaction with having to wait to receive services, not obtaining information and/or services desired, and not receiving services delivered in a manner convenient to families or tailored to their child's and family's needs.

Participants in this study identified more positive qualities and outcomes of EI than aspects of EI they thought needed to be changed. Neither the service provider's discipline nor the service delivery setting was related consistently to positive or negative experiences and perceptions of EI services. The positive aspects most frequently mentioned were access to services and the personal characteristics of service providers (subthemes of the first theme in research question 3); both of these fit the framework for family-centered practices designed by Trivette and Dunst (1998), which includes relational and participatory practices categories. Relational practices are the behaviors associated with effective interaction (e.g., showing compassion, listening effectively, communicating nonjudgmentally, identifying family strengths, and showing sensitivity to family beliefs and values) that have been identified in other studies (e.g., Haring & Lovett, 2001; Applequist & Bailey, 2000).

Parents in this study made more positive comments (47 statements) than negative (27 statements) regarding participatory practices. However, in regard to relational practices, parents expressed dissatisfaction with their service providers (14 statements), almost as often as they expressed satisfaction (17 statements). Several other studies have indicated that the relationship with the service provider seems to impact families as much as, if not more than, the services themselves (e.g., Nachshen & Jamieson, 2000; Wang, Mannan, Poston, Turnbull, & Summers, 2004; Brookman-Frezee, 2004; Fine & Nissenbaum, 2000; Summers et al., 2007; Siklos & Kerns, 2006); this study supports inclusion of providers' relational practices as components of an effective service delivery model (see, e.g., Dunst & Dempsey, 2007).

In this study parents were asked to describe both the family's role and the EI provider's roles during EI sessions. Some families reported participating minimally in intervention sessions, while others reported active involvement that included facilitating child development, sharing information with the service provider, observing, and developing new skills. This finding of varying levels of participation is consistent with findings from research on families of children receiving EI services for other disabilities (e.g., Applequist & Bailey, 2000; Bailey, Scarborough, & Hebbeler, 2003). Parents' reported level of participation (i.e., the role of the parent in intervention) was not related to parental satisfaction with services. However, trusting provider-family relationships that allow straightforward communication about level of parental involvement may be a critical element of EI service provision for families of children with ASD; for example, other research has found that mothers of children with ASD experienced fewer symptoms of depression when their child received more hours of Applied Behavior Analysis (ABA) per week, but those who spent more hours involved in their child's ABA program felt more stress (Schwichtenberg & Poehlmann, 2007).

The findings of this study also call attention to some unique needs of parents of young children with ASD. Participants referred to the importance of a skilled interventionist who assisted in promoting children's communication and social skills, enhancing the child's ability to engage in interactive play, and reducing challenging behaviors; attention to these specific areas may be of particular importance, as other research indicates that families of children with ASD may experience higher levels of stress if a child's challenging behavior does not improve (e.g., Gray, 2002; Hastings, 2003). It may be particularly important for professionals who provide EI services for young children with ASD to keep abreast of effective and evidence-based principles and practices when providing services to young children with ASD such as using positive behavior supports to intervene with challenging behaviors, building spontaneous and functional child communication, and promoting child engagement in meaningful age-appropriate learning opportunities (see Rogers & Vismara, 2008).

Other research has indicated that the timing of when parents learn that a child has a disability affects their response to the situation (Nelson, 2002), and families of young children at risk for ASD are frequently unaware of this disability until the child is approximately 2 years of age, while other families may be aware of a disability much sooner (Layne, 2007). Therefore, the initial experiences of families who have children with ASD may be different from those of other families, requiring flexible interpersonal skills and different supportive behaviors on the part of the service provider (Nissenbaum, Tollefson, & Reese, 2002).

Limitations

Data collected were from one EI program in one state, limiting the ability to generalize findings. In order to ensure confidentiality, a limited amount of demographic information was collected, making it difficult to determine if family experiences were related to specific family characteristics such as socioeconomic status, or educational or cultural background. The inability to generalize from these data is a limitation to this study.

Future Research

This research adds to the literature by looking at the role of the provider from the parent's perspective. The majority of participants indicated that, regardless of setting or the discipline of the service provider, their children's EI providers facilitated child development, shared information, or assisted the family in developing new skills. These roles are similar to those that parents reported for themselves. The finding that parents and service providers assumed similar roles suggests the likelihood that many of the participating families were respected as equal and contributing partners in the intervention process. Parent-professional partnerships in which parents feel respected may result in empowerment of the families, which in turn may result in more competent parenting (Dunst, 2000; Dunst & Trivette, 1996). For families receiving a diagnosis of autism (often after months or years of uncertainty), EI services that enhance parental ability to cope effectively and to participate in meaningful ways in the EI process are of critical importance. In this study, the majority of parents expressed their desire to be involved in all aspects of EI service delivery.

Future research at the national level should target the experiences of families with a young child at risk or identified with ASD, investigating on a large scale how various family characteristics (such as education, income, and severity of disability) may influence their experiences with EI.

Conclusions: Implications for Service Provision

The importance of EI services that attend to the uniqueness of each individual and emphasize the quality of life when partnering with families and other collaborative agencies has been addressed in the related literature, as have focusing on individual needs of children with ASD and the needs and preferences of their families (see, e.g., R. Turnbull, A. Turnbull, Wehmeyer, & Park, 2003; Summers, Hoffman, Marquis, Turnbull, & Poston, 2005; Meadan, Halle, & Ebata, 2010; Whitaker, 2002). Findings of this study also indicate that families will respond positively to being able to participate in EI sessions at levels that are comfortable for them, and to information and services that help them understand autism in general and their children's specific needs.

Further, it is critical to reflect upon relational practices and the interpersonal skills of service providers that are considered critical components of family centered EI services by Dunst, Trivette, and Hamby (2007) and others. Early interventionists whose interactions when partnering with families are supportive, collaborative, and positive are more likely to develop strong collaborative relationships characterized by caring and commitment. Such relationships appear to be essential to parents' feeling that EI is successfully meeting the child's and the family's needs.

Research involving families and their experiences and perceptions with EI can have direct implications for early intervention practice, as families are essential participants in intervention (Bruder, 2000). This study begins to identify some unique EI needs and preferences of families of young children with ASD, but additional research is needed to further explore the distinct challenges encountered by families of young children with ASD and the specific EI service delivery needs they express. Because service adequacy affects families' quality of life, it is critical to continue emphasizing the importance of relational and participatory practices in personnel preparation and professional development programs and to continue listening to the voices of families in early intervention research.

References

Applequist, Karen; & Bailey, Donald. (2000). Navajo caregivers' perceptions of early intervention services. *Journal of Early Intervention, 23*(1), 47-61.

Bailey, Don; Scarborough, Anita; & Hebbeler, Kathleen. (2003). *Families' first experiences with early intervention.* Menlo Park, CA: SRI International.

Bailey, Donald; Hebbeler, Kathleen; Scarborough, Anita; Spiker, Donna; & Mallik, Sangeeta. (2004). First experiences with early intervention: A national perspective. *Pediatrics, 113*(4), 887-896.

Baio, Jon. (2012). Centers for Disease Control. Retrieved April 30, 2013, from http://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm?s_cid=ss6103a1_w

Barnett, Steven. (1995). Long-term effects of early childhood programs on cognitive and school outcomes. *Future of Children, 5*(3), 25-50.

Beals, Katharine. (2004). Early intervention in deafness and autism. *Infants and Young Children, 17*(4),284-290.

Brantlinger, Ellen; Jimenez, Robert; Klingner, Janette; Pugach, Marleen; & Richardson, Virginia. (2005). Qualitative studies in special education. *Exceptional Children, 71*(2), 195-195.

Brookman-Frazee, Lauren. (2004). Using parent/clinician partnerships in parent education programs for children with autism. *Journal of Positive Behavior Interventions, 6*(4),195-213.

Bruder, Mary Beth. (2000). Family-centered early intervention: Clarifying our values for the new millennium. *Topics in Early Childhood Special Education, 20*(2), 105-115.

Crais, Elizabeth R.; Roy, Vicky P.; & Free, Karen. (2006). Parents' and professionals' perceptions of the implementation of family-centered practices in child assessments. *American Journal of Speech-Language Pathology, 15*(4), 365-377.

Dunst, Carl J.; & Dempsey, Ian. (2007). Family–professional partnerships and parenting competence, confidence, and enjoyment. *International Journal of Disability, Development and Education, 54*(3), 305-318.

Dunst, Carl J.; Hamby, Deborrah W.; & Brookfield, Jeffri. (2007). Modeling the effects of early childhood intervention variables on parent and family well-being. *Journal of Applied Quantitative Methods, 2*(3), 268-288.

Dunst, Carl J., & Trivette, Carol. M. (1996). Empowerment, effective helpgiving practices and family centered care. *Pediatric Nursing, 22*(4),334–337.

Dunst, Carl J. (2000). Revisiting "Rethinking early intervention." *Topics in Early Childhood Special Education, 20*(2),95-104.

Dunst, Carl J.; Trivette, Carol M.; & Hamby, Deborah W. (2007). Meta-analysis of family-centered help giving practices research. *Mental Retardation and Developmental Disabilities Research Reviews, 13*(4), 370-378.

Epley, Pamela H.; Summers, Jean A.; & Turnbull, Ann P. (2011). Family outcomes of early intervention: Families' perceptions of need, services, and outcomes. *Journal of Early Intervention, 33*(3), 201-219.

Farrell, Anne F. (2009). Validating family-centeredness in early intervention evaluation reports. *Infants & Young Children, 22*(4), 238-252.

Fine, Marvin J.; & Nissenbaum, Michal S. (2000). The child with disabilities and the family: Implications for professionals. In Marvin J. Fine & Richard L. Simpson (Eds.), *Collaboration with parents and families of children and youth with exceptionalities* (pp. 3–26). Austin, TX: PRO-ED.

Gray, David E. (2002). Ten years on: A longitudinal study of families of children with autism. *Journal of Intellectual and Developmental Disability, 27*(3),215-222.

Grindle, Corina F.; Kovshoff, Hanna; Hastings, Richard P.; & Remington, Bob. (2009). Parents' experiences of home-based applied behavior analysis programs for young children with autism. *Journal of Autism and Developmental Disorders, 39*(1), 42-56.

Groves, Robert M.; Fowler, Floyd J.; Couper, Mick P.; Lepkowski, James M.; Singer, Eleanor; & Tourangeau, Rodger. (2009). *Survey methodology* (2nd ed.). Hoboken, NJ: John Wiley.

Guralnick, Michael J. (1997). *The effectiveness of early intervention*. Baltimore, MD: Paul H. Brookes.

Gwynne, Kerry; Blick, Bijou A.; & Duffy, Gabrielle M. (2009). Pilot evaluation of an early intervention programme for children at risk. *Journal of Pediatrics and Child Health, 45*(3),118-124.

Haring, Kathryn A.; & Lovett, David L. (2001). Early intervention and early childhood services for families in rural areas. *Rural Special Education Quarterly, 20*(3), 3-11.

Harrison, Melody; Dannhardt, Margaret; & Roush, Jackson. (1996). Families' perceptions of early intervention services for children with hearing loss. *Language, Speech, and Hearing Services in Schools, 27*(3), 203-214.

Hastings, Richard P. (2003). Child behavior problems and partner mental health as correlates of stress in mothers and fathers of children with autism. *Journal of Intellectual Disability Research, 47*(4-5),231-237.

Henderson, Kelly. (2009). *Autism spectrum disorders: State part C and part B initiatives to serve a growing population.* Project Forum. Retrieved April 30, 2013, from http://www.nectac.org/

Hurtubise, Karen; & Carpenter, Christine. (2011). Parents' experiences in role negotiation within an infant services program. *Infants & Young Children, 24*(1), 75-86.

Jackel, Bernadette; Wilson, Michelle; & Hartmann, Elizabeth. (2010). A survey of parents of children with cortical or cerebral visual impairment. *Journal of Visual Impairment & Blindness, 104*(10), 613-623.

Jackson, Carla W.; Traub, Randi J.; & Turnbull, Ann P. (2008). Parents' experiences with childhood deafness: Implications for family-centered services. *Communication Disorders Quarterly, 29*(2), 82-98.

Jung, Lee Ann; & McWilliam, R. A. (2005). Reliability and validity of scores on the IFSP rating scale. *Journal of Early Intervention, 27*(2), 125-136.

Layne, Christina M. (2007). Early identification of autism: Implications for counselors. *Journal of Counseling & Development, 85*(1), 110-114.

Lazara, Alex; Danaher, Joan; & Goode, Sue. (2012). *Part C infant and toddler program federal appropriations and national child count 1987-2012. Chapel Hill:* University of North Carolina, FPG Child Development Institute, National Early Childhood Technical Assistance Center. Retrieved April 30, 2013, from http://www.nectac.org/~pdfs/growthcomppartc.pdf

Lovett, David L.; & Haring, Kathryn A. (2003). Family perceptions of transition in early intervention. *Education and Training in Developmental Disabilities, 38*(4), 370-377.

Meadan, Hedda; Halle, James W.; & Ebata, Aaron T. (2010). Families with children who have autism spectrum disorders: Stress and support. *Exceptional Children, 77*(1), 7-36.

Miles, Matthew B.; & Huberman, Michael. (1994). *Qualitative data analysis* (2nd ed.). Thousand Oaks, CA: Sage.

Nachshen, Jennifer; & Jamieson, Janet. (2000). Advocacy, stress, and quality of life in parents of children with developmental disabilities. *Developmental Disabilities Bulletin, 28,* 39-55.

Nelson, Antonia M. (2002). A metasynthesis: Mothering other-than-normal children. *Qualitative Health Research, 12*(4), 515-530.

Nissenbaum, Michal S.; Tollefson, Nona; & Reese, R. Matthew. (2002). The interpretative conference: Sharing a diagnosis of autism with families. *Focus on Autism and Other Developmental Disabilities, 17*(1), 30-43.

Otero-Fernandez, Ruth. (2004). *Puerto Rican family involvement in the orientation and mobility training of their children with visual impairments.* Florida State University. ProQuest Dissertations and Theses. DR will CHECK APA

Patterson, Stephanie; & Smith, Veronica. (2011). The experience of parents of toddlers diagnosed with autism spectrum disorder in The More Than Words parent education program. *Infants and Young Children, 24*(4), 329-342.

Rodger, Sylvia; Keen, Deb; Braithwaite, Michelle; & Cook, Shannon. (2008). Mothers' satisfaction with a home based early intervention program for children with ASD. *Journal of Applied Research in Intellectual Disabilities, 21*(2), 174-182.

Rogers, Sally J.; & Vismara, Laurie A. (2008): Evidence-based comprehensive treatments for early autism. *Journal of Clinical Child & Adolescent Psychology, 37*(1), 8-38.

Schwichtenberg, A. J.; & Poehlmann, Julie. (2007). Applied behaviour analysis: Does intervention intensity relate to family stressors and maternal well-being? *Journal of Intellectual Disability Research, 51*(8), 598-605.

Shannon, Patrick. (2004). Barriers to family-centered services for infants and toddlers with developmental delays*. Social Work, 49*(2), 301-308.

Siklos, Susan; & Kerns, Kimberly A. (2006). Assessing need for social support in parents of children with autism and Down syndrome. *Journal of Autism and Developmental Disorders, 36*(7), 921-933.

Summers, Jean A.; Hoffman, Lesa; Marquis, Janet; Turnbull, Ann; & Poston, Denise. (2005). Relationship between parent satisfaction regarding partnerships with professionals and age of child. *Topics in Early Childhood Special Education, 25*(1), 48-58.

Summers, Jean Ann; Marquis, Janet; Mannan, Hasheem; Turnbull, Ann P.; Fleming, Kandace; Poston, Denise J.; Wang, Mian; & Kupzyk, Kevin. (2007). Relationship of perceived adequacy of services, family–professional partnerships, and family quality of life in early childhood service programmes. *International Journal of Disability, Development and Education, 54*(3), 319-338.

Talay-Ongan, Ayshe. (2001). Early intervention: Critical roles of early childhood service providers. *International Journal of Early Years Education, 9*(3), 221-228.

Trivette, Carol M.; & Dunst, Carl J. (1998, December). *Family centered help giving practices*. Paper presented at the 14th annual Division for Early Childhood International Conference on Children with Special Needs, Chicago.

Trivette, Carol. M.; & Dunst, Carl. J. (2005). DEC recommended practices: Child-focused practices. In Susan Sandall, Mary Louise Hemmeter, Barbara J. Smith, & Mary E. McLean (Eds.), *DEC recommended practices: A comprehensive guide for practical application* (pp. 107–206). Longmont, CO: Sopris West.

Trudgeon, Clare; & Carr, Deborah. (2007). The impacts of home-based early behavioural intervention programmes on families of children with autism. *Journal of Applied Research in Intellectual Disabilities, 20*(4),285-296.

Turnbull, Ann P.; Summers, Jean A.; Turnbull, Rud; Brotherson, Mary J.; Winton, Pam; & Roberts, Richard. (2007). Family supports and services in early intervention: A bold vision. *Journal of Early Intervention, 29*(3), 187-206.

Turnbull, Rutherford H.; Turnbull, Ann P.; Wehmeyer, Michael L.; & Park, Jiyeon. (2003). A quality of life framework for special education outcomes. *Remedial and Special Education, 24*(2), 67-74.

U.S. Department of Education. (2004). Individuals with Disabilities Improvement Act of 2004, 20 U.S.C. 5 1400 et seq.

U.S. Department of Education, Office of Special Education Programs, Data Analysis System (DANS), OMB #1820-0557: "Infants and Toddlers Receiving Early Intervention Services in Accordance with Part C," 2009. Data updated as of July 15, 2010.

Wade, Catherine M.; Mildon, Robyn L.; & Matthews, Jan M. (2007). Service delivery to parents with an intellectual disability: Family-centered or professionally centered. *Journal of Applied Research in Intellectual Disabilities, 20*(2), 87-98.

Wang, Mian; Mannan, Hasheem; Poston, Denise J.; Turnbull, Ann P.; & Summers, Jean Ann. (2004). Parents' perceptions of advocacy activities and their impact on family quality of life. *Research and Practice for Persons with Severe Disabilities, 29*(2),144-155.

Webster, Alec; Feiler, Anthony; Webster, Valerie; & Lovell, Claire. (2004). Parental perspectives on early intensive intervention for children diagnosed with autistic spectrum disorder. *Journal of Early Childhood Research, 2*(1), 25-49.

Whitaker, Philip. (2002). Supporting families of preschool children with autism: What parents want and what helps. *Autism, 6*(4),411-426.

Wieder, Serena; & Greenspan, Stanley I. (2003). Climbing the symbolic ladder in the DIR model through floor time interactive play. *Autism, 7*(4), 425-435.

Wilcox, Jeanne M.; Dugan, Lauren M.; Campbell, Philippa H.; & Guimond, Amy. (2006). Recommended practices and parent perspectives regarding AT use in early intervention. *Journal of Special Education Technology, 21*(4), 329-354.

Yoshikawa, Hirokazu. (1995). Long-term effects of early childhood programs on social outcomes and delinquency. *Future of Children, 5*(3), 51-75.

Author Information

Christan Grygas-Coogle, Ph.D., is a teaching assistant professor in the Department of Special Education at West Virginia University. Her graduate training was at Florida State University. She teaches courses leading to preschool special needs certification as well as graduate level courses in early intervention and early childhood special education at WVU. Dr. Grygas-Coogle's research interests include family centered practice, autism, and personnel preparation.

Christan Grygas Coogle, Ph.D.
College of Education and Human Services
West Virginia University
Morgantown, West Virginia 26505
E-mail: christan.coogle@mail.wvu.edu

Amy R. Guerette, Ed.D. is the associate dean for academic affairs and an associate professor in the Visual Disabilities Program. She currently serves on national and state committees in the field of visual impairment and deafblindness. Her research interests include the development of literacy skills in students with visual impairments and deafblindness, the use of paraprofessionals, early intervention services, educator preparation, and quality of life and services for adults with visual impairments.

Mary Frances Hanline, Ph.D., is a professor in the School of Teacher Education at Florida State University. Her graduate training was at the University of California, Berkeley, with San Francisco State University. She has more than 25 years of experience with university teaching and research in early childhood special education (ECSE). She coordinates the ECSE and distance learning MS program at FSU. Her research interests include play-based intervention, inclusion, and supports to young learners with severe disabilities in high-quality inclusive early childhood programs. She has directed or co-directed multiple OSEP personnel preparation grants, a project of national significance, a model demonstration project, and two research grants totaling more than $7.8 million in external funding.