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Family-Centered Practice in the Field of Early Intervention

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FAMILY-CENTERED PRACTICE IN THE FIELD OF EARLY INTERVENTION

by

Catherine A. Collie

B.S., Southern Illinois University, 1990

A Research Paper

Submitted in Partial Fulfillment of the Requirements for the
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RESEARCH PAPER APPROVAL

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TITLE: FAMILY-CENTERED PRACTICE IN THE FIELD OF EARLY INTERVENTION

MAJOR PROFESSOR: Dr. Deborah A. Bruns

In Early Intervention (EI), family-centered practices are recommended and family-centered services are espoused as the main delivery method. Yet, EI service providers may not implement this approach. This literature review will examine provider and family perspectives of the delivery of family-centered services in the context of the Division for Early Childhood's recommended practices indicators of family-centered services. Findings indicated a gap between what families and providers believed were ideal family-centered practices and what was actually being implemented in EI. Barriers such as training for providers and families and lack of appropriate resources were identified. Implications for the future are evaluation of the fidelity and methodology of family-centered services training and increased resource allocation in order to increase opportunities for teaming, co-treatment, training, and professional development for providers and families in order to enhance implementation of family-centered services.

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CHAPTER 1

INTRODUCTION

The primary function of Early Intervention (EI) according to The Division for Early Childhood (DEC) is to promote parent-professional collaboration with respect for family values and diverse cultures and to support infants and children with special needs and their families in planning and implementing intervention services (Sandall, Hemmeter, Smith, & McLean, 2005). This view is coupled with legal changes in 1997 which emphasized implementation of family-centered practices by mandating the development of the Individual Family Service Plan (IFSP). Development and implementation of an IFSP required greater parent involvement in the decision making process and an emphasis on the distinctive nature of providing services to infants, toddlers, and their families (Sandall et al., 2005). Bailey, Buysse, Edmondson, and Smith (1992) stated the characteristics unique to family-centered services were: (a) children in EI do not function independently of their families therefore decisions and interventions affect more than the child, they affect the family, (b) an approach which includes family support and resources is likely to be more effective, (c) family members determine their level of involvement in decision making and service implementation, and (d) family goals should take priority in the provision of services and supports.

Beginning in the early 1980s, theoretical frameworks for working with families were developed. In the late 1980s, Dunst offered empowerment as a new vision for working with families with children with disabilities from birth to age three (Dunst, Trivette, & Deal, 1988). These frameworks were supported by tenets to family-centered services such as help-giving practices and family empowerment. According to Dunst, Trivette, and Deal (1994), the family-centered model is operationalized each time a provider or help-giver interacts with a family.

Family needs are identified, family functioning style is defined, and existing and potential supports and resources are determined. These three parts are aligned by the help-giving behavior of providers. This was in contrast to the prevailing perspective on “parent involvement” which was described as parents participating in activities or interventions that professionals determined important (McWilliam, Tocci, & Harbin, 1998). The same authors deemed the term “parent involvement” simplistic and one-sided.

At this time, Dunst described a continuum of professional viewpoints on service delivery from professionally-centered, to family-allied, to family-focused, to family-centered. The professionally-centered model views professionals as the expert on child and family challenges, and does not value family involvement in the decision making process (Dunst et al., 1988). According to Dunst et al. (1988) the family-allied model also views professionals as the experts on decision making and implementation of services and families exist to follow up on these recommendations while being supervised by professionals. In the family-focused model, the family is viewed as capable of making decisions but is limited to the support and resource role for their child. Finally, the family-centered model considers families as equal partners and interventions are strengths based, individualized, and focus on family needs. These professional viewpoints vary in the degree of family participation which was determined by providers due to provider perceptions of families’ competencies and ability to understand their strengths, assets, and resources. Therefore, the level of family-centeredness in interventions is directly affected.

Legal requirements have also impacted family-centered service delivery in EI. In 1975, the Education for All Handicapped Children Act of 1975 (PL 94-142) required free and appropriate public education for school-age children with disabilities. Reauthorization in 1986 (PL 99-457) created Part H, known as EI, for infants and toddlers. In the 1990s, the legislation

was renamed the Individuals with Disabilities Education Act (IDEA) and Part H became Part C. IDEA included the addition of comprehensive services for children ages birth to five years. This was a marked change for services for infants and toddlers and their families. EI initially began as an optional, state funded program void of federal regulation. States had the option of offering services to children with disabilities or delays age birth to three years.

The 1997 reauthorization of IDEA was renamed the Individuals with Disabilities Education Improvement Act (IDEIA) and, for the first time, fully funded Part C as federal mandated services for children age birth to three including the requirement for family-centered services incorporating the child's needs into the context of the family beliefs, priorities, and needs and the family becomes the focus for planning. The reauthorization of IDEIA in 2004 PL 108-446 (Individuals with Disabilities Education Improvement Act, 2004) continued to support parent participation in the decision making process and attainment of desired family outcomes.

As theoretical changes influenced legal changes, the Individualized Family Service Plan (IFSP) signaled a shift with its emphasis on family support and decision making to assist child development and family outcomes. In the early 1990s the Division for Early Childhood (DEC) of the Council for Exceptional Children (CEC) determined clear standards for EI and Early Childhood Special Education (ECSE) providers did not exist. In 1993, the DEC published the *DEC Task Force on Recommended Practices* and in 1996, released a book entitled *Early Intervention/Early Childhood Special Education Recommended Practices* (Odom & McLean, 1996). This book described 14 areas of practice to serve as quality indicators for EI/ECSE providers such as assessment, family participation, IFSPs/IEPs, and transition (Odom & McLean, 1996).

Several years later, the DEC produced an updated review of the literature which included discussions with stakeholders in the field of EI/ECSE including practitioners, parents, and policy makers. This process ended in the release of the *DEC Recommended Practices in Early Intervention/Early Childhood Special Education* (Sandall, McLean, & Smith, 2000). The 14 areas of practice were reduced to seven strands: (a) assessment, (b) child-focused interventions, (c) family-based practices, (d) interdisciplinary models, (e) technology applications, (f) policies, procedures, and systems change, and (g) personnel preparation. Each strand has corresponding recommended practices. For example, the family-based strand recommends families and professionals share responsibility and work collaboratively (Sandall, McLean, & Smith, 2000).

In 2005 the DEC updated the 2000 book and released the *DEC Recommended Practices: A Comprehensive Guide for Practical Application in Early Intervention/Early Childhood Special Education* (Sandall et al., 2005) which defined and operationalized “recommended practices” in seven strands. Family-centered practices and is one strand in this discipline-specific set of guidelines.

Trivette and Dunst were asked to write the family-centered strand of the DEC Recommended Practices (2005). The authors operationalized family-centered service delivery to four tenets: (a) collaboration between parents and providers, (b) strengthening family functioning, (c) individualized and flexible practices, and (d) an emphasis on a strength- or asset-based approach (Trivette & Dunst, 2005). Specifically, the recommended practices and associated indicators describe how implementation of the tenets could be demonstrated. For example, EI providers were also responsible for sharing information in a manner that meets each family’s needs and strengthens family functioning and, in turn, parenting confidence and competence. In order to ensure practices are individualized and flexible, providers must

understand each family's situation and implement intervention plans, resources, and assessments accordingly. Providers must also recognize that family circumstances change over time.

Interventions, supports, and resources should incorporate family priorities and preferences, beliefs and values, and be culturally responsive (Sandall et al., 2005).

Dunst, Boyd, Trivette, and Hamby (2002) conceptualized family-centered practices as including relational and participatory components. The relational component builds the parent-provider relationship through active listening, respect, belief in family abilities, and a positive attitude. The participatory component focuses on family empowerment through providers using a flexible, individualized approach, collaborating with families, and actively involving families in the decision-making process. Shared responsibility and collaboration between providers and families involves both parties working together toward the common goal of increasing positive outcomes for the child and the family. For example, a study by Dunst et al. (2002) examined parent perceptions related to Dunst's participatory and relational components with the service delivery methods of varying degrees of family involvement. The results support findings that more family-centered programs utilize the participatory and relational components. These conclusions suggest the importance of both components when investigating family-centered practices. It appears the current law and the operationalization of "recommended practices" influenced the shift in EI to family-centered services by focusing on family involvement and individualized practices.

This review of the literature investigates family and provider perspectives on the implementation of the four tenets of family-centered services as stipulated in the *DEC Recommended Practices* (2000, 2005). Taken together, these practices inform the provision of family-centered practices in EI.

CHAPTER 2

METHOD

Articles included in this literature review were primary sources reporting studies involving descriptions or implementation of family-centered practices by Early Intervention or Early Childhood (EC) providers. The articles were published between the years 1997 and 2008 in peer-reviewed journals. Articles were initially located through an online search using *Google Scholar*. The search terms of “family-centered services, family-centered practices, and family-centered behaviors” were used for open dates, sorted by relevance. The search was narrowed by using the search terms “early intervention” alone and then in combination with “family-centered services, practices, and behaviors”. Considered articles were primary sources of study data. As articles were located, the ten year span was altered to include articles by Dunst, Trivette, and McWilliam. The span of 1997 to 2007 encompassed works by these authors and correlated to the period of time when family-centered services became a federal mandate and considered “recommended practice”. Studies conducted outside of the United States were eliminated due to variations in federal mandates for family-centered practices in EI services in other countries. These results produced nine studies.

A second search was conducted using *Academic Search Premier* through *EBSCOhost* which uncovered several more articles. As articles were within the inclusion parameters reference lists were reviewed and articles using the determined dates of 1997-2007 and studies of family-centered services in Early Intervention conducted in the U.S. were included. Next, individual studies from a meta-analysis of studies of family-centered practices conducted by Dunst, Trivette, and Hamby were cross-referenced with the set parameters of time and topics. Five additional studies were located, bringing the total to 16.

Within these parameters, sixteen studies were identified examining provider and/or family perspectives or behaviors. Of these sixteen studies, eight studies examined family perspectives of family-centered EI services. Six additional studies reported data from families and providers. The final two studies examined provider behaviors or perspectives on family-centered services. Research methodology included survey, interview, and focus groups.

Based on committee recommendations, a third search was conducted to include studies conducted between 2008 and 2013. *Academic Search Premier* through *EBSCOhost* and *Google Scholar* were utilized. Articles in peer reviewed journals, relating to family-centered practices, services, and behaviors in Early Intervention, and conducted in the U.S. between 2008 and 2013, were included. Four additional studies were located, bringing the total to 20.

Journals included in this review were *American Journal of Speech-Language Pathology*, *Exceptional Children*, *Family Relations*, *International Journal of Disability, Development and Education*, *Journal of Applied Quantitative Methods*, *Journal of Early Intervention*, *Journal of Emotional and Behavioral Disorders*, *Journal of Intellectual and Developmental Disability*, *Physical Therapy*, *Social Work*, *Topics in Early Childhood Special Education*.

CHAPTER 3

LITERATURE REVIEW

Partnership and Collaboration between Families and Providers

The first of the four tenets of family-centered services of the *DEC Recommended Practices* (Trivette & Dunst, 2005) is collaboration between parents and providers. According to Blue-Banning, Summers, Frankland, Nelson and Beegle (2004) there are six elements that define the collaborative family-provider partnership: (a) communication which should be positive and respectful and involves listening, sharing resources, and honesty, (b) commitment demonstrated by a shared dedication to family goals through being sensitive, accessible, and flexible, (c) equality involves empowering families by making them equal partners in the decision making process during assessment, interventions, and follow-up, (d) skills which include taking action when necessary, meeting the individual needs of the child or family, and being willing to learn, (e) trust between families and providers, and (f) respect exemplified when parties are non-judgmental, courteous, and value the child. EI programs focusing more on the family engage in meaningful partnerships between families and providers (Bailey et al., 1998).

Several studies investigated the collaborative relationship between EI providers and families. McBride and Peterson (1997) reported 47% (n=15) of EI service coordinators felt difficulties in the family-provider relationship as a barrier to service delivery. McWilliam et al. (1998) examined family-centered practices in terms of six providers' philosophies and behaviors identified as family-centered in the literature. One theme was the lack of emotional distance between the partnership between the provider and the client exemplified by providers being regarded as concerned family friends and not maintaining the traditional professional-client relationship. Positiveness was another theme described by providers not passing judgment and

demonstrating enthusiasm for working with families. Providers showed sensitivity toward cultural differences and responsiveness exemplified by providers taking action when a want or need was identified. The final theme was friendliness and honesty of providers. Campbell and Halbert (2002) studied providers' perspectives on how to improve EI services. One of the six themes was increasing opportunities for teaming and collaboration by facilitating improved communication, providing communication books for all team members to use, and once teams get to know each other, they should revisit goals and concerns. The authors stated their findings indicate an increased need for collaboration since collaboration was reported to be a barrier to service delivery. Additionally, providers described how collaboration could be improved by more timely communication, increased opportunities for communication such as communication books, and greater occasions for co-treatment. Providers also felt increased meeting time, increased teaming by different agencies, and monthly meetings for team members to discuss clients would increase collaboration and partnership between providers and positively affect outcomes for families.

Sawyer and Campbell (2009) examined provider beliefs about EI practices by studying 211 providers. Participants were asked to sort 20 recommended EI practices, such as services focused on family identified needs and opportunities for collaboration among providers, on a continuum of strongly agree to strongly disagree. Providers strongly disagreed there were no collaborative opportunities for providers from different disciplines to work together when they provide services for the same family. In other words, providers felt there were collaborative opportunities to work with providers from other disciplines when providing services for a family. Participants indicated they believed in collaboration between providers. Additionally the

participants felt collaborative opportunities between families and providers, existed (Sawyer & Campbell, 2009).

Family perspectives on the collaborative relationship between EI providers and families were also studied. Petr and Allen (1997) studied the collaborative relationship by examining family perceptions of the importance and frequency of family-centered behaviors demonstrated by providers. Parents rated the following EI provider behaviors as moderately important: (a) listens, (b) treats us with respect, (c) accepts our family as part of the team, and d) asks me what I want when making decisions. These behaviors demonstrate the importance of collaboration to families. O'Neil, Palisano, and Wescott (2001) found mothers were pleased with their partnership with EI providers when they were helpful, knowledgeable, and positive. Additionally, the authors found EI providers who believed mothers to be equal partners in the decision making process, hence collaborative principle, had positive influence on mothers' perceptions of family-centered behaviors. Summers et al. (2007) found provider-family partnerships affect a family's quality of life suggesting relationships with providers are an important part of service delivery. Furthermore, Bruder & Dunst (2008) surveyed 346 parents and caregivers of children receiving EI services in order to identify child, parent, family and provider variables associated with variations in identified provider practices. One of the findings indicated the use of family-centered practices directly affects the parent-provider relationship. Again, these traits correspond to Trivette and Dunst's first tenet of family-centered practices, partnership and collaboration between families and providers (Trivette & Dunst, 2005).

According to Blue-Banning and colleagues (2004), equal partnership in development and delivery of interventions and services supports collaboration. Wesley, Buisse, and Tyndall (1997) conducted a series of focus groups of EI providers and families and results pointed to

elements of collaboration. Families reported when they were offered limited choices regarding available services and were not offered support on how to advocate for their child by evaluating or creating opportunities within the community. Providers said in order to create choices for services for families they had to be “deceptive” or “work around the system” which does not support collaboration.

Home visits and during assessment are two opportunities for collaboration between families and providers. McBride and Peterson (1997) led a study which examined the content of home visits. Results found that 45% of the time EI providers were interacting with the parent and the child, leaving 55% where they were not. This study also found that EI providers spent over half their time in direct teaching rather than modeling behaviors for parents to participate in interventions. Crais, Roy, and Free (2006) looked at family-provider partnerships in the assessment process. They found families were not included in pre-assessment planning and had a limited role in their child’s actual assessment. Families not being treated as equal partners beginning with the intake process and continuing through the decision making process is one of elements of collaboration defined by Blue-Banning et al. (2004).

An additional study conducted by Brotherson et al. (2010) interviewed families and providers to investigate factors contributing to or impeding the establishment of family-provider partnerships. Findings showed, in order to strengthen the partnership, the provider must share a sense of urgency to provide interventions in order to create better outcomes for families. Additionally, the authors found the stress of multiple challenges some families experience coupled with the demands providers feel due to administrative expectations, may negatively impact the quality of the partnership. Brotherson et al. went further to state providers’ and families’ emotional needs must be met in order to establish successful partnerships.

In 2010, Salisbury, Woods, and Copeland completed an exploratory case study of six EI providers implementing family-centered services in a diverse urban community. As part of the training, the term “collaborative consultation” was used to describe the relationship the provider had with a family. During the collaborative consultation process, the provider was responsive to changing family needs, promoted parent learning, and used preferred family activities and routines in order to implement family-centered services through promoting family-provider partnerships. Results showed post-training, five of the six providers experienced positive changes in their perspectives of family-centered collaborative consultation. As a whole, these studies demonstrate that collaboration is occurring but may not be fully implemented by EI providers.

Strengthening Family Functioning through Access to Formal and Informal Information, Resources, and Supports

The second tenet of family-centered services is practices that strengthen family functioning. Availability of formal and informal information, resources, and supports help promote positive outcomes for children and families (Campbell & Halbert, 2002; Mahoney & Bella, 1998; Romer & Umbreit, 1998; Wesley et al., 1997). As families negotiate the EI system, their needs, concerns, and priorities may change. For example, during the intake process, families may need formal supports such as information on how the EI system works or connections with other programs or agencies. Families may also need informal supports such as friends and neighbors, family members, other families with a child with a disability, or community activities. After receiving services for six months or a year, families may need formal supports such as information on how to prepare for IFSP meetings, the transition from EI to the school system, or additional information about assistive technology. In addition to these formal

supports, informal supports may be needed to assist parents in advocating for their child or finding additional community activities to participate in.

Studies have also examined EI service providers' strengthening family function through provision of family-centered services. McWilliam et al. (1998) examined family-centered practices based on the philosophies and behaviors of service providers whose behaviors exemplified family-centered practices as identified in the literature. One of the six themes discussed was the importance of service providers having knowledge of child and community skills such as economic status of the community, including current changes in major employers in the area. Second, service providers were also able to examine and describe stigmas or perceptions within the community such as "lack of quality day-care". Third, service providers were knowledgeable about the positive and challenging aspects of their communities. Fourth, the providers were proactive and eager to work with other community agencies in a collaborative manner by visiting local preschool classrooms or the local library to discover firsthand what other programs offer. These provider attributes support the family-centered practices of provision of information, use and knowledge of community resources, and the ability to mobilize supports for parents.

In 2002, a study conducted by Campbell and Halbert examined practitioner perspectives about changes to the EI system in order to improve the quality of services received by children and families. One of the six themes involved formal resources such as offering parent trainings and workshops to increase parent participation in EI sessions. In addition to identifying indicators of family-centered services which strengthen family functioning, it is necessary to determine the positive effects on families. In a study conducted by Petr and Allen (1997), parents' perceptions of the importance and frequency of family-centered behaviors were

evaluated. Some of the behaviors with a large discrepancy between “important” and “frequently performed” were help obtaining services from other agencies and programs, getting help from our family, friends, and communities, and help acquiring wanted or needed information. These results indicate the families’ unfulfilled desire for information, resources, and supports.

Similarly, Romer and Umbreit (1998) studied family satisfaction when a family-centered model is used for service coordination. Each month families were sent a 10 item checklist of family-centered behaviors. Five behaviors focused on providing families formal and informal information, resources, and support. Families reported a higher degree of satisfaction and lower degree of dissatisfaction with services when these family-centered behaviors were implemented. This study supports how access to resources for families in EI can positively affect their satisfaction level.

These studies imply that family-centered service delivery provides resources, support, and information for families (Wesley et al., 1997). Additionally, family centered behaviors positively affect families by increasing their satisfaction ratings of EI services (Romer & Umbreit, 1998). It appears providers emphasize formal supports yet families gain information through informal supports (Wesley et al., 1997). This highlights a gap between important family-centered behaviors and frequently performed family-centered behaviors (Petr & Allen, 1997). The disharmony of what is being provided to families and providers and what should be provided to families and providers becomes apparent.

Individualized and Flexible Practices

Individualized and flexible practices is the third tenet of family-centered behaviors according to Trivette and Dunst (2005). McWilliam et al. (1998) studied providers who demonstrated family-centered practices identified in the literature such as individualization of

practices. Findings indicate the providers understood each family's individual needs and used an individualized and flexible approach to service provision. O'Neil et al. (2001) surveyed 25 providers and 75 mother-child dyads to determine if family-centered practices were instituted during physical therapy sessions. Providers reported interventions were not always individualized due to administrative guidelines and expectations. Additionally providers felt the formal nature of the EI system and programs or agencies that work with EI are too rigid to allow individualization of practices.

Another approach to individualizing services is to be flexible with the frequency, duration, intensity, and number of services offered depending on family priorities and needs. Improved service coordination and consolidation or centralization of services can aid in this pursuit. Campbell and Halbert (2002) found providers indicated a desire for flexibility to increase frequency and duration of therapy, the ability to involve other disciplines when needed for consultation or co-treatment, and the support to increase the number of providers so children can receive services based on family needs instead of available providers. Additionally, providers sought increased opportunities for training on co-treatment to address individualization.

When comparing family and provider perspectives, researchers found families felt interventions should be determined by their child's characteristics while providers focused on the availability of services to determine the number and type of interventions and services (Campbell & Halbert, 2002; McBride & Peterson, 1997; McWilliam et al., 1998; O'Neil et al. 2001; Shannon, 2004; Summers et al., 2007; Wesley et al., 1997).

Assessment occurs at the beginning of the intake process and is, therefore, the first opportunity for providers to implement individualized and flexible practices. Crais et al. (2006)

examined the degree to which providers and families reported family-centered practices were implemented during the assessment process. The largest discrepancies between family and provider viewpoints were for the following practices: (a) families were present for meetings, (b) families reviewed reports and made suggestions, and (c) families wrote down observations during assessment (p. 373). These findings may indicate the need for increased individualization of the assessment process.

Flexibility is another method to individualize services. McBride and Peterson (1997) examined the content of home visits to explore the extent to which home visits were individualized. Families were divided into groups based on their access to resources (adequate vs. limited) and care-giving demands (greater vs. fewer) of their child. Families with children with greater care-giving demands tended to have two or more adults involved, such as providers from other disciplines, in joint interaction with the child. Additionally, individualization was demonstrated when the content of the home visits for families with adequate resources was directed toward child development and for families with limited resources, the provider was more likely to address family issues.

According to *DEC Recommended Practices* (Trivette & Dunst, 2005) one of the indicators for individualized support is interventions are tailored to the child's and family's preferences. In order for parent-provider teams to address the individual needs of a family, it is important for providers and/or parents to be aware of all available services. Through focus groups of providers and families, Wesley and colleagues (1997) found parents whose children were receiving EI services were not consistently aware of services and struggled to understand the interrelationship of programs and agencies. An example of an unmet need related to individualization was described by Summers et al. (2007). The authors found that families in

their sample experienced unmet information needs on sibling support programs and respite care. Results from this study suggest providers need to devise creative ways to serve families through uncovering family preferences. Trivette and Dunst (2005) emphasize addressing each family member's priorities and preferences such as offering materials in different languages or using CDs rather than printed materials. Overall, these studies found working with families during assessment, understanding each family's unique needs, and tailoring interventions to the family's and child's characteristics rather than services that are available, assist providers in ensuring practices individualized and flexible.

Empowerment through a Strengths- or Assets-Based Approach

The final element of family-centered practices according to Trivette and Dunst (2005) is use of a strengths- or assets-based approach which is a significant predictor of empowerment (Dempsey & Dunst, 2004) and empowerment is a construct which is identified by implementation of key elements such as a strengths- or asset-based approach (Dunst et al., 1994). According to Dunst et al. (1994), empowerment is based on the principle that families have capabilities and providers should use a strengths-based, proactive approach with families. Additionally, empowerment is exemplified via collaboration, demonstrating mutual respect and shared decision-making as well as increasing parent knowledge and skills with corresponding increases in self-efficacy, and self-esteem.

Several studies examined help-giving practices. Dunst et al. (2002) identified the relational and participatory components of help-giving practices as key attributes of family empowerment. In review, relational help-giving is characterized by active and reflective listening, empathy, warmth, trustworthiness, belief in a help-seeker's capabilities, and the recognition and acknowledgement of help seeker's strengths. Participatory help-giving is

characterized by active participation in identifying and implementing interventions, encouraging help-seeker responsibility for acquiring knowledge and skills to solve problems, and strengthening existing capabilities.

The participatory and relational behaviors focus help-giver involvement in the intervention process therefore increasing the empowerment of help-seekers (Dunst et al., 2002). Dunst et al. (2002) went further and examined the continuum of professionally centered, family allied, and family centered models in comparison to the participatory and relational help-giving practices for families in Pennsylvania and North Carolina. Mothers of children receiving EI services were surveyed. The study found in professionally centered programs, relational and participatory help-giving practices were rated lower in terms of use of help-giving behaviors. In contrast, relational and participatory help-giving practices were rated higher, or occurred more frequently in family-centered practices. These results indicate the type or degree of family orientation affects the degree of participatory and relational help-giving practices being used. Overall, the results show the relational and participatory practices are what distinguish family centered programs from other family oriented models (Dunst et al., 2002).

Judge (1997) surveyed 69 families in eastern Tennessee who had children with disabilities or at risk for developmental outcomes receiving services. The author investigated the relationship between help-giving practices and parental sense of control and self-efficacy from families' perspectives. Families indicated home based interventions offered more opportunities for help-giving behaviors due to increased sense of control. Judge (1997) concluded that home based settings offer more opportunities for providers to implement help-giving behaviors to empower families. The findings demonstrate the positive effects for families are increased when help-giving practices assist families to understand their child's needs, recognize their strengths

and resources to meet those needs, and feel in control over desired outcomes. In addition, Dempsey and Dunst (2004) surveyed 67 families in North Carolina receiving either home-based, center-based, or a combination of intervention. The authors found the only significant predictor of empowerment was provision of help-giving practices. These findings support relational help-giving practices and add to previous findings to support the relationship between help-giving practices and family empowerment.

The family-centeredness of EI practices was directly related to perceived control over EI supports and resources which leads to empowerment. Two hundred fifty families were surveyed (Dunst, Hamby, & Brookfield, 2007) and help-giving practices were rated based on the extent to which families felt providers were being responsive to parent requests, using active and reflective listening, and being empathetic. The survey included items for families to rate the extent to which they felt they had control over the services received and the ability to successfully gain resources. Family well-being was found to be related to personal control and family characteristics.

A number of studies examined empowerment. Shannon (2004) surveyed 20 providers and 22 families in Virginia receiving IDEA Part C services. Providers and families identified several ways to empower families. Suggestions were using a strength-based approach, and providers initially need to address basic family needs such as child care, current housing situation, or transportation. Subsequently, providers assist families in identifying and utilizing supports and resources. Next, providers can supply needed information on child development or the EI system to empower the family. Finally, providers can assist families in gaining skills to implement interventions so decision making belongs to the family. Summers et al. (2007) found family quality of life as contributing to empowerment when studying the relationship between

perceived service adequacy, family-professional partnerships, and family quality of life. Furthermore, the authors found the manner in which services were delivered to 180 families receiving EI, such as in a respectful and positive mode, influences families as the actual service delivery does. Dunst and Dempsey (2007) reiterated Summers' findings that it is how practitioners interact with families that accounts for an increased family sense of control which is an element of empowerment.

According to Trivette and Dunst (2005) one of the indicators of implementing a strengths based approach is family and child strengths and assets are used to engage families in participatory experiences. Practices should build on existing parenting competence and confidence and promote the family and provider acquisition of new knowledge and skills to strengthen competence and confidence. Help-giving behaviors which lead to empowerment assist families and providers to apply these strength based approaches.

In summary, partnership and collaboration between families and providers, strengthening family functioning through access to formal and informal information, resources, and supports, individualized and flexible practices, and empowerment through a strength- or asset-based approach are the four tenets of family-centered services (Trivette & Dunst, 2005). Utilizing these tenets through recommended practices helps promote positive family outcomes.

CHAPTER 4

DISCUSSION

The literature review examined perspectives of family-centered practices by families receiving EI services and EI providers. Findings included increasing opportunities for collaboration and partnership between families and providers (Campbell & Halbert, 2002), availability of formal and informal information, resources, and supports to strengthen family functioning (Campbell & Halbert, 2002; Mahoney & Bella, 1998; Romer & Umbreit, 1998; Wesley et al., 1997), the need for providers to understand each family's individual needs and use an individualized and flexible approach to service provision (McWilliam et al., 1998), and empowerment based on the principle that families have capabilities and providers should use a strengths-based, proactive approach with families (Dunst et al., 1994).

Along with these findings, there appear to be various barriers to the implementation of family-centered practices identified in the literature such as family expectations (Shannon, 2004), training of providers (Campbell & Halbert, 2002), and lack of time and resources (Campbell & Halbert, 2002). Additionally the dissonance between the philosophy of family-centered practice and the implementation of behaviors corresponding to the philosophy emerged (Crais et al., 2006; McBride & Peterson, 1997).

Limitations

Based on review of the literature several issues arose. Of the studies reviewed, eleven were conducted in the northeastern part of the United States (NC, NH, PA, and TN). Several of the studies acknowledged the demographics of the northeast were not typical of the remainder of the United States (Crais et al., 2006; Dempsey & Dunst, 2004; Dunst & Dempsey, 2007; Judge, 1997). Therefore, generalization to other states or geographic regions is limited.

Recommendations to conduct studies in other geographic locations may be warranted as well as studies that are national in scope.

The term “early intervention” varied in definition from state to state. Most studies were conducted with families and providers serving children from birth to five although Early Intervention is commonly considered only for children with disabilities from birth to age three. Generalizations specifically to family-centered practices with families with an infant or toddler with disabilities or developmental delays may be limited. Several studies involved small numbers of participants which may affect generalization as well (Mahoney & Bella, 1998; McBride & Peterson, 1997; McWilliam et al., 1998; Romer & Umbreit, 1998; Wesley et al., 1997).

Implications

This literature review found several implications for practice. Provider and family collaboration, strengthening families through resources and supports, ensuring practices are individualized, and using a strength based approach to empower families all combine into family-centered services for families. Yet, there appears to be a research to practice gap, therefore changes may be warranted.

Recommendations for evaluation of the fidelity of family-centered services training may be useful. Romer and Umbreit (1998) described a lack of consistency in training across university curricula and continuing education workshops as a potential influence on the implementation of family-centered services by providers. Lack of time and resources also affects delivery of family-centered practices. McBride and Peterson (1997) found providers spent a majority of their time “teaching” the child a new skill as opposed to “modeling or

facilitating” interventions to family members. Sawyer and Campbell (2009) found families were often observers of provider-child interactions where providers directly taught children.

From a provider perspective, it is less time consuming to lead planned activities to “teach” skills rather than using naturally occurring activities to help a parent facilitate their child’s skill development. This may occur because training focuses on strategies to encourage child development rather than a focus on providing family-centered services (McBride & Peterson, 1997; McWilliam et al., 1998; Summers et al., 2007). In addition, when appropriate training is available, individual providers may not implement the skills and knowledge gained during training or professional development. Feedback and self-reflection then become an essential and ongoing part of the training process. Therefore, training, monitoring, and evaluation of implementation of family-centered services may be warranted.

Another recurring theme addressed training and professional development for providers. Literature indicates family-centered services have a positive effect on families and the DEC recommends using family-centered practices, yet parents describe variability in the degree of implementation of family-centered services (Mahoney & Bella, 1998). Making changes in how providers are trained by examining university curricula and corresponding courses and field placements is needed. In addition, utilizing current technology may assist providers in implementing family-centered behaviors. For example, Campbell and Halbert (2002) found providers would like to have increased technology such as laptops and computerized forms, compensation for visits missed or canceled by families, and smaller caseloads to increase the time available to spend on meeting family needs, related to the provision of family-centered practices.

In order to accommodate family preferences, providers requested more opportunities for teaming and co-treatment (Campbell & Halbert, 2002). Additionally the authors found providers wanted more control over training methods and content. Providers suggested more independence to choose training topics, small group or team based trainings as opposed to large group trainings, and increased training on particular strategies including addressing behavior challenges. Furthermore, instead of the standard lecture and discussion style training, additional opportunities for providers to go into the field and implement their learning then utilize feedback, self-reflection, and follow-up to ensure philosophies are being put into practice. Further support was exemplified by Sawyer and Campbell (2009) in a study of providers, preservice students, and higher education faculty. Participants also felt collaboration was essential for increased learning opportunities for children and role release through transdisciplinary services better address developmental needs (Sawyer & Campbell, 2009)

Future Research

Looking toward the future, closing the gap between which practices should be implemented and which practices are implemented will be important based on the positive effects of family-centered services on families. The four tenets described by Trivette and Dunst (2005) in the DEC Recommended Practice indicators may need to be revisited. The review of the literature found fewer articles referencing and operationalizing individualized and flexible practices as an element of family-centered practices.

One theme that emerged as a potential barrier to family-centered services focused on the families' understanding, expectations, and ability to participate in family-centered services. Even though family-centered services are considered "recommended practice" for providers (Trivette & Dunst, 2005); families may prefer a child-focused agenda. Providers may need to be

understanding of families where parents want an “observer” rather than “interventionist” role. Differing family characteristics may affect delivery of family-centered services. Busy schedules, other family members’ needs, and money issues may take priority over interventions. Therefore, the addition of or integration of family characteristics into the four tenets of family-centered practices may be necessary and should be validated through empirical studies.

Additionally, families may not understand what family-centered services are and expect services to be child-focused as they are in other contexts such as teachers in the primary grades or visits with their child’s medical professionals. Differing family needs may require innovative methods to share information. Terminology may be confusing to families and educators tend to have their own “language” (Petr & Allen, 1997; Shannon, 2004). Providers need vary communication styles to fit each family’s needs. Everyday language and clarification of unfamiliar terminology helps families make informed decisions for their children. Examining perceptions about effective communication between providers and families could help to bridge the information gap. Research examining families’ understanding of family-centered services may be necessary. In addition, examination of the effectiveness of parent trainings upon entrance to the EI system may be warranted.

Conclusion

The literature suggests barriers to family-centered service as well as improvements that can be made by partnership and collaboration between families and providers, strengthening families through resources and supports, implementing individualized and flexible practices, and empowering families through strength-based approaches. It will take a joint effort by providers, families, policy makers, researchers, trainers, administrators, and higher education programs to achieve this goal (Campbell & Halbert, 2002).

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