

FAMILY-CENTERED CARE AS A PREDICTOR OF EARLY INTERVENTION
OUTCOMES FOR ETHNICALLY DIVERSE FAMILIES

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ABSTRACT

Genna R. Durante: Family-Centered Care as a Predictor of Early Intervention Outcomes for
Ethnically Diverse Families
(Under the Direction of Rune J. Simeonsson)

Family centered-care is considered the gold standard approach in pediatric healthcare by numerous medical societies, healthcare systems, and legislative bodies governing the care of children. The current study utilized data from the National Early Intervention Longitudinal Study (NEILS) to examine family-centered care in the provision of early intervention services. The study had two main goals: (a) to examine the experiences of racially and ethnically diverse families in early intervention with regard to family-centered service delivery, and (b) to investigate whether or not perceived family-centered care could predict better outcomes for ethnically diverse families receiving early intervention services. Results found that race/ethnicity was significantly predictive of perceived family-centered care in early intervention, with Caucasian families significantly more likely to perceive high levels of family-centered care than African American and Hispanic families. In addition, greater family-centered care was predictive of higher perceived impact of early intervention services for African American families, and a reduction in the rate of special education services among Hispanic children in kindergarten. Family-centered care is discussed as an important variable in improving early intervention outcomes for racially and ethnically diverse families.

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Introduction

Research in child development has provided overwhelming evidence for the importance of intervention in the first three years of life for children with disabilities and children at risk for developmental delays (Casto & Mastropieri, 1986, Guralnick, 1997, Guralnick, 2005). The last three decades have been rich with studies supporting the use of early intervention for improving the cognitive, academic, and psychosocial development of young children and the caregiving capabilities of their families (Campbell & Ramey, 1994; Schweinhart et al., 2005). However, findings from the National Early Intervention Longitudinal Study (NEILS) demonstrated that racially and ethnically diverse families experience less positive outcomes compared to White families (Bailey et al., 2005). These results are of concern, and suggest that more research is needed to better understand this pattern. This study examined the role of family-centered care in the provision of early intervention services to racially and ethnically diverse families. Family centered-care (FCC) is considered the gold standard approach in pediatric healthcare by numerous medical societies, healthcare systems, and legislative bodies governing the care of children (Kuo et al., 2013). It has been well documented that family-centered care is associated with positive outcomes for families, including improved family functioning, access to care, systems of care, and parenting competency (Kuhlthau et al., 2011). This study examined the relationship between early intervention outcomes, as experienced by racially and ethnically diverse families, and the provision of family-centered care.

Review of the Literature

The rationale to support the connection between family-centered care and improved early intervention outcomes for racially and ethnically diverse families was first explored with a thorough review of the literature. This review addressed (a) early intervention legislation and efficacy, (b) the National Early Intervention Longitudinal Study, and (c) family-centered care. Included in the literature review on family-centered care were discussions on the provision of family-centered care to diverse populations, and the relationship between culture and principles of family-centered care. Following this review, limitations in the previous literature were identified, which informed the development of research questions for the present study. Names for various racial and ethnic groups vary throughout the literature review in order to reflect the labels used by the referenced studies' authors.

Early Intervention Legislation and Efficacy

The benefits of early intervention have proven to be so advantageous to vulnerable children and families that early intervention services are now federally mandated (U.S Department of Education, 2002). In 1986, the Infants and Toddlers Disabilities Act was introduced as an amendment to the Education for All Handicapped Children Act (EAHCA) (U.S Department of Education, 2002). In 1990, the EAHCA was renamed as the Individuals with Disabilities Education Act (IDEA), which was divided into four parts: A, B, C, and D. The provisions of the Infants and Toddlers Disabilities Act became Part C of IDEA. Under Part C, states receive federal grants to develop and implement comprehensive early intervention programs for children from birth to three and their families (U.S Department of Education, 2002). Infants and toddlers qualify for early intervention service if they have a delay in any of

the following five areas: cognitive, physical, communication, social or emotional, or adaptive functioning (U.S Department of Education, 2002). They may also receive services if they have a diagnosed medical or mental health condition that puts them at high risk for having a developmental delay (U.S Department of Education, 2002).

Part C was established to address four specific goals (U.S Department of Education, 2002). First, it would enhance the developmental outcomes of children with disabilities. Second, early intervention programs would reduce future costs of special education services among school-age youth by serving them at a younger age. Third, early intervention would increase the likelihood that children with disabilities could grow up to be independent adults. Fourth, services would enhance families' competency to meet the developmental needs of their child (U.S Department of Education, 2002).

The Early Intervention Collaborative Study (EICS) was a landmark study of early intervention, completed in association with 29 programs in Massachusetts and New Hampshire (Shonkoff, Hauser-Cram, Krauss, Upshur, & Sameroff, 1992). This study aimed to address three main objectives: (a) to enhance understanding of variations in the development of children with disabilities in early intervention, (b) to study the mediating influences of family variables and services on child and family outcomes, and (c) to create conceptual models of child and family development to inform future research in the field of children with special needs. EICS researchers followed 190 infants and toddlers with disabilities and their families through their first year of participating in early intervention services, and studied the relationship among child and family characteristics, mediators, and child and family outcomes. Outcomes were assessed

through a range of parent self-report measures, observational measures, and developmental evaluations.

Results from the EICS found that there was no single variable that predicted both child and family outcomes at the end of 12 months of early intervention services. The severity of child's psychomotor impairment was found to be the single most consistent predictor of child outcome measures. Children with the greatest psychomotor impairment made the least amount of developmental progress, and were described by the researchers as the most vulnerable group in early intervention. In addition, the researchers found that children with seizure disorders were also quite vulnerable, as they demonstrated a particularly slow rate of development during the first year of early intervention (Shonkoff et al., 1992).

With regard to family outcomes, results from the EICS varied. Overall, families of children with motor impairments experienced the least positive outcomes. Families of children with more severe impairments had an increased likelihood of perceiving a higher detrimental impact of raising a child with a disability on the family over time. Parenting stress was not found to change substantially following the year of early intervention services, but families that received services from a single early intervention discipline demonstrated a decrease in parenting stress. Maternal social supports increased for families participating in early intervention program models that encouraged parents to interact with each other or involved a range of service providers. Maternal interactive behaviors improved slightly over the course of early intervention services but did not change substantially for most mothers. The EICS researchers emphasized that conceptualizing early intervention and disability is a complex and multidimensional process. They pointed to the need for future research to utilize both short-term and longitudinal

investigations of early intervention to better understand the adaptive outcomes of young children with disabilities and their families (Shonkoff et al., 1992).

Another notable study of early childhood intervention was the Carolina Abecedarian Project, which followed 111 infants born into poverty beginning in 1972 (Campbell & Ramey, 1994). The majority of participants (98%) were African American. Infants were randomly assigned into four groups. In one group, infants received high quality educational intervention during the preschool years only. In another group, infants received the intervention during both the preschool years and primary grades. In the third group, infants received no intervention during the preschool years, but received high quality educational intervention during the primary grades. In the fourth group, infants received no study-implemented interventions. The curriculum for the early childhood intervention had a strong focus on language development and pre-literacy skills and also addressed the child's social, emotional, and cognitive development. The school-age intervention involved assigning students a Home School Resource Teacher and providing an individualized activity plan based on the children's learning needs. Progress was monitored through follow-up studies at ages 12, 15, 21, and 30 (Campbell & Ramey, 1994; Campbell et al., 2012). Results found that long-lasting cognitive and social benefits were associated with the early childhood intervention (Campbell et al., 2002). At age 21, participants who received the preschool intervention had significantly higher cognitive and academic scores, had completed significantly more years of total education, were more likely to be engaged in a skilled job, were more likely to attend a 4-year college, and were less likely to become teenage parents (Campbell et al., 2002). In addition, young adults in the preschool intervention group had slightly higher cognitive test scores compared to participants in the control groups. When comparing

participants that received only the preschool intervention with participants that received only the grade school intervention, young adults provided with the preschool intervention had better outcomes (Campbell et al., 2002). At the age 30 follow-up study, adults who participated in the preschool program had attained more years of education compared to the control group. They were four times more likely than the control group to have earned a college degree by age 30 (Campbell et al., 2012).

The Carolina Abecedarian Project was significant in demonstrating that high quality intervention during the early childhood years can make a positive difference in the life trajectory of children at considerable risk for poor outcomes. This study, along with others such as the HighScope Perry Preschool study (Schweinhart et al., 2005), demonstrated that early intervention does not just improve child outcomes, but may help to close the achievement gap for racial/ethnic minorities and children raised in poverty (Perez-Johnson & Maynard, 2007). Research shows that racial/ethnic minority children and White children enter school with different levels of pre-academic skills, and these differences become exacerbated in the following years (Lin & Harris, 2008). By fourth grade, academic disparities are evident, with African American children scoring more than 25 points lower and Hispanic children scoring more than 15 points lower than White children on reading and math assessments (Lin & Harris, 2008). Achievement gaps have been found to persist through middle school and high school, which has captured the attention of many researchers, clinicians, and educators (Perez-Johnson & Maynard, 2007). Advocating for high quality early intervention services has become more than a priority for early educators; it has become a priority for administrators, politicians, lawmakers, and all that are concerned about children's futures.

The National Early Intervention Longitudinal Study

The National Early Intervention Longitudinal Study (NEILS) was the only national study to examine the impact of Part C early intervention services on children and families (Hebbeler et al., 2007). Conducted for the U.S. Department of Education's Office of Special Education, the NEILS followed a nationally represented sample of 3,338 infants, toddlers and their families who entered into early intervention services between 1997 and 1998 (Hebbeler et al., 2007). Data collection continued through the participants' kindergarten year (Hebbeler et al., 2007). NEILS investigators asked the following broad research questions: *Who are the children and families receiving early intervention services? What early intervention services do participating children and families receive, and how are those services delivered? What are the costs of those services? What outcomes do participating children and families experience? How do outcomes relate to variation in child and family characteristics and services provided?* The NEILS researchers described the study framework as transactional/ecological, while also integrating family systems theory (Hebbeler et al., 2007).

In order to address the NEILS research questions, data collection took place at specific intervals between children's entrance into early intervention services and the spring of their kindergarten year (Hebbeler et al., 2007). Family interviews were conducted by telephone within 16 weeks of early intervention enrollment, when the child turned 36 months and transitioned out of early intervention services, and when the child began kindergarten. The interviews included questions about the child's characteristics, the child's functioning and development, the family's experiences with early intervention services, and the family's household characteristics. In order to obtain a clear picture of early intervention services received, service providers completed

service record questionnaires every six months for child participants enrolled in the study. When children reached kindergarten, their teacher filled out a two-part survey, which included questions about their educational progress, social skills, parent involvement, transition into kindergarten, and special education services (Hebbeler et al., 2007).

The NEILS findings yielded important data about the children and families receiving early intervention services, as well as their experiences and outcomes. A comprehensive discussion of findings from NEILS analyses is beyond the scope of this paper, but can be found in the official NEILS Data Reports (Bailey, Hebbeler, & Scarborough, 2003; Bailey et al., 2004; Javitz et al., 2002; Hebbeler et al., 2007; Levin et al., 2004). With regard to the characteristics of children and families receiving early intervention, results found that African American children and children living in poverty were over-represented in early intervention compared to the general population (Scarborough et al., 2004). Children entering early intervention were also more likely to have mothers who had not gone to college compared to the general population (Scarborough et al., 2004). Speech/communication impairment or delay was the most common area of eligibility for entry into early intervention, with at least 39 percent of children fitting into this category (Scarborough et al., 2004). Children in early intervention also were more likely to have compromised birth histories and be in poor overall health (Scarborough et al., 2004). With regard to early intervention service providers, most professionals were female, White, highly educated, and unlikely to speak a language besides English (Hebbeler et al., 2007).

Overall, results from NEILS were somewhat encouraging with regard to child outcomes (Hebbeler et al., 2007). Parents reported that by 36 months, many of the children in early intervention had met expected developmental milestones (Hebbeler et al., 2007). Health status

improved for 21 percent of children in early intervention, stayed the same for 64 percent of children, and became worse for 15 percent of children, based on parent report (Hebbeler et al., 2007). Communication continued to be an area of difficulty for some children, with 22 percent of parents reporting that their child had a lot of trouble communicating, 32 percent of parents reporting that their child had a little trouble communicating, and 46 percent of parents reporting that their child communicates well (Hebbeler et al., 2007). The kindergarten surveys, completed by the former early intervention participants' teachers, showed that 32 percent of children who were enrolled in early intervention were not receiving special education services in kindergarten (Hebbeler et al., 2007). Overall, former early intervention participants were slightly below average academically, and continued to have some difficulties communicating and making friends (Hebbeler et al., 2007). However, most teachers indicated that former early intervention participants were within normal limits for their age with regard to behavior and social skills (Hebbeler et al., 2007). Child outcomes from the NEILS must be interpreted with caution because data were based on parent and teacher report. As with all studies in early intervention, it is difficult to tease apart what skills gained were due to early intervention services and what outcomes were a result of developmental maturation.

Unlike many intervention studies that focus solely on children's outcomes, the NEILS focused substantially on the outcomes of families. Legislation, family advocacy efforts, theory and research have demonstrated that a main focus of early intervention is to support the families of children with disabilities (Bailey et al., 1999; Bailey et al., 2004; Dunst, 2002). Despite the importance of family outcomes, there is a lack of clarity regarding what these outcomes should be, and if programs are responsible for family outcomes in addition to child outcomes. Bailey

and colleagues (1998) developed a framework for assessing family outcomes through a set of survey questions, which were later incorporated into the NEILS family interviews. The first three questions addressed the families' perceptions of the early intervention experience: (a) *Does the family see early intervention as appropriate in making a difference in their child's life?* (b) *Does the family see early intervention as appropriate in making a difference in their family's life?* (c) *Does the family have a positive view of the professionals and the special service system?* The second set of questions addressed the perceived impact of early intervention on the family: (d) *Did early intervention enable the family to help their child grow, learn, and develop?* (e) *Did early intervention enhance the family's perceived ability to work with professionals and advocate for services?* (f) *Did early intervention assist the family in building a strong support system?* (g) *Did early intervention help enhance an optimistic view of the future?* (h) *Did early intervention enhance the family's perceived quality of life?* (Bailey et al., 1998).

Results from the NEILS were quite encouraging with regard to family outcomes. At the 36-month telephone interview, most parents saw early intervention as making a difference in their children's life and in their family's life (Bailey et al., 2004). Most parents reported that they were much better off (59%) or somewhat better off (23%) as a result of the services they received (Bailey et al., 2004). Parents also agreed or strongly agreed that they were competent in caring for their child's basic needs (99%) and helping their child to learn and develop (96%) (Bailey et al., 2004). However, parents reported much greater difficulty figuring out their child's behavior, with only 66 percent of parents feeling comfortable handling behavior problems (Bailey et al., 2004). Parents reported feeling comfortable working with professionals (95%) and knowing how to advocate for services (90%) (Bailey et al., 2004). While most parents felt that

they had a support system (89%), a substantial minority (36%) reported that they had little chance to take part in community activities (Bailey et al., 2004). Parents also reported that the professionals they worked with helped them feel hopeful about the future (94%) and enhanced their quality of life (91%) (Bailey et al., 2004).

A more complex analysis of the NEILS child and family outcomes was conducted using structural equation modeling to examine the relationship between families' formal and informal supports, parents' reported impact of early intervention on their child and family, and whether these relationships were mediated by optimism in their family's future or confidence in parenting (Bailey et al., 2007). Formal supports were assessed by parents' ratings of early intervention service quality, and informal supports were assessed by parents' ratings of support in their community outside of intervention services. Quality of services was determined by parents' responses to three survey items in which they were asked to rate the quality of their child's therapy services, intervention services, and the quality of information and help the family received. Results indicated that parents' ratings of service quality received by their child were directly related to the perceived impact of early intervention on their child. However, ratings of early intervention quality received by their child was not related to parents' optimism about the future, confidence in parenting, or perceived overall impact of services on their family. Parents' ratings of family service quality were related to ratings of overall impact of services on their family and optimism about their family's future, but were not related to their confidence in parenting. Informal supports reported by parents were not related to their perceived impact of early intervention services on their child or family (Bailey et al., 2007).

While family outcomes were generally positive, NEILS researchers went a step further by conducting a logistic regression analysis to determine if less positive outcomes were associated with specific demographic variables (Bailey et al., 2004). Because the responses were skewed and non-normally distributed, the researchers completed an item-by-item analysis to separate families into categories of more positive outcomes and less positive outcomes following specific guidelines (see Bailey et al., 2004). Twenty-five percent of the NEILS families were determined to have less positive outcomes (Bailey et al., 2004). Results showed that aside from child's health status, race/ethnicity was a significant predictor of less positive outcomes. Controlling for all other variables, families of Caucasian children were significantly more likely to be in the positive outcomes group compared to families of children from all other racial/ethnic groups combined (Bailey et al., 2004). Families of African-American children were 2.13 times as likely to be in the less positive outcomes group compared to families of Caucasian children (Bailey et al., 2004). Racial/ethnic minority families, low-income families, and families with less educated caregivers were more likely to report that it took a lot of effort to find out about early intervention services and get services started, and were less satisfied with their level of involvement in decision making (Bailey et al., 2004). These families were also more likely to feel that early intervention professionals did not respect their cultural background or ignored their family's opinions. In addition, these families were less likely to believe that early intervention professionals made them feel hopeful about their child's future (Bailey et al., 2003). Results from structural equation modeling showed that non-Caucasian families were more likely to report lower quality of services received by their family and lower overall impact of early intervention on their family (Bailey et al., 2007).

Clear discrepancies in responses by racial/ethnic groups emerged on certain items. For example, 30 percent of Caucasian parents agreed that they often had a difficult time figuring out what to do about their child's behavior, compared to 40 percent of African American parents, 41 percent of Hispanic parents, and nearly 46 percent of multiracial parents (Bailey et al., 2004). These results are of concern considering the large body of research supporting the fact that behavior management is a critical component of effective parenting and supporting children's healthy development, especially for children with disabilities (Hauser-Cram et al., 2001; Sanders, Mazzucchelli, & Studman, 2004). While there is limited research on parents' perceived behavior management abilities, research on parenting self-efficacy shows that perceived abilities directly impact the quality of care provided to children (Sanders & Woolley, 2005). Children with behavior problems are likely to come from families that experience considerable stress (Short & Brokaw, 1994), instability (Fergusson & Lynskey, 1993), and use punitive disciplinary practices (Short & Brokaw, 1994). A study by Scarborough and colleagues (2007) found that at entry to early intervention, Black toddlers were rated to have more difficult behaviors compared to White toddlers. In addition, toddlers from families with an annual income of \$25,000 or less were rated to have more difficult behaviors than toddlers from families with an annual income of more than \$75,000 (Scarborough et al., 2007). These children and their families are clearly in need of high quality intervention services that provide substantial support with behavior management. However, African American families seem to be least satisfied with early intervention services overall and have less positive outcomes compared to other early intervention participants (Bailey et al., 2004), which is a discrepancy that merits further

investigation. Further research is needed to better understand how early intervention service delivery could potentially improve the less positive outcomes experienced by these families.

Family-Centered Care

As previously stated, early intervention under Part C of IDEA was developed to address the needs of the family, not just the needs of the child. This idea of family-centered services is highlighted in the development of the Individualized Family Service Plan (IFSP), which is developed by the early intervention service provider and family at the start of early intervention. The IFSP outlines the services that will be provided to the child and the child's family over the course of services (Hebbeler et al., 2007).

Family-centered service delivery, or family centered-care, has received extensive review in the literature over the last three decades, specifically related to the medical care of children with special healthcare needs (Hostler, 1991). With the advancement of technology, more children with disabilities and chronic illnesses are surviving at higher rates, which have prompted a reevaluation of provisions of medical and developmental services to children and their families (Hostler, 1991). Family-centered care is a healthcare approach that emphasizes the important role of the family in the healthy development of the child (Petr & Allen, 1997). Family-centered care is considered the gold standard for pediatric healthcare by medical societies, healthcare systems, legislative bodies, the Institute of Medicine, and Healthy People 2020 (Kuo et al., 2013). While there is some agreement on the principles of family-centered care, a consensus definition of family-centered care has not yet been reached (Kuo et al., 2013). Family-centered care principles developed by groups such as the Maternal and Child Health Bureau and the American Academy of Pediatrics include information sharing, respecting and

honoring differences, partnership and collaboration, negotiation, and care in context of family and community (Kuo et al., 2013). In a literature review, Dempsey and Keen (2008) outlined four critical practice principles that drive the implementation of family centered services. First, the family is the constant in the child's life, not the professionals. Second, the family is best positioned to determine the needs and well-being of the child. Third, the best way to help the child is to also help the family, which may involve understanding the family's community and providing information to meet their needs. Fourth, family-centered care emphasizes partnerships and collaboration with families, family choice and involvement in decision making regarding the provisions of service, showing respect and affirming families' strengths, and enhancing families' control over their services.

Although family-centered care is widely endorsed, it is not sufficiently implemented into clinical practice (Kuo et al., 2012). There is a lack of adequate research examining the impact of family-centered care, likely due to a lack of validated measures that assess it (Kuo et al., 2012). Procedures to measure family-centered care have taken several approaches. Some instruments are based on staff's self-evaluation of their services. Another approach involves rating videos of exchanges between staff and parents. The most common approach to measuring family-centeredness is parent reports of the services they have received. One example of a parent report is the Measure of Process of Care (MPOC) developed by King, Rosenbaum and King in 1995. The original MPOC contains 56 items which have five factor analytically determined scales: enabling and partnership, providing general information, providing specific information about the child, coordinated and comprehensive care for the child and family, and respectful and supportive care. The MPOC also comes in a shorter 20-item version. This scale has been used

primarily in the assessment of service provision to families of children with neurodevelopmental conditions (Kuo et al., 2012). Other parent report measures that address some of the family-centered care principles include the Family Empowerment Scale (Singh et al., 1995), Helping Practices Scale (Trivette & Dunst, 1994), Enabling Practices Scale (Dempsey, 1995), and the Measure of Beliefs about Participation in Family-Centered Services (King et al., 2004).

Dempsey and Keen (2008) conducted a literature review of 35 studies that addressed family-centered practices for families of children with disabilities between 1993 and 2007. They found considerable variation in parents' perceptions of family-centered principles across different kinds of services. Although several types of services, including early intervention, use a family-centered mission statement, having a family-centered mission statement did not guarantee that parents perceived services to be family-centered. Dempsey and Keen described the research on family-centered practice to be in the adolescent stage of development. While family-centered care has influenced service philosophy and orientation, especially with regard to young children with disabilities, more research needs to be conducted to assess family-centered practice and the important outcomes that are believed to be associated with this approach (Dempsey & Keen, 2008).

Despite a slow start, the number of studies examining the relationship between family-centered practice and child and family outcomes is growing. Recent studies have linked family-centered care with numerous benefits for children with special healthcare needs (Kuhlthau et al., 2011), including improvements in health status (Dunst & Trivette, 2009; Kuo, Bird, & Tilford, 2011) and quality of life (Moore, Mah, & Trute, 2009), as well as decreased behavioral problems (Graves & Shelton, 2007). Family-centered care has also been associated with improvements in

family functioning, access to care, systems of care, satisfaction with services, and communication between parents and service providers (Kuhlthau et al., 2011). In addition, family-centered intervention has been found to improve parenting competency, efficacy and control (Heller, Miller, & Hsieh, 1999; Keen et al., 2010). Heller and colleagues (1999) found that a family-centered intervention was effective in increasing care-giving self-efficacy for parents of adults with developmental disabilities compared to a control group. Keen and colleagues (2010) similarly found that a family-centered intervention for families of children with autism led to increased parenting competence compared to a control group. The impact of family-centered services has also not been adequately investigated with respect to child development outcomes, although a study by Dunst (1999) found the extent and nature of parenting supports to be the only significant predictor of child progress in a multivariable model.

Provision of family-centered care to diverse populations. Given the empirically supported positive impact of family-centered care on numerous child and family outcomes, it should be expected that this approach be applied consistently in service delivery to children and families across all cultural, racial and socioeconomic groups. However, a study by Coker, Rodriguez and Flores (2010) demonstrated significant racial, ethnic, and language disparities for family-centered care among children with special healthcare needs. The authors used data from the 2005-2006 National Survey of Children with Special Healthcare Needs (NS-CSHN), which is a telephone survey sponsored by the Maternal and Child Health Bureau. The data set contained over 40,000 respondents. The NS-CSHN contained six questions to assess family-centered care based on five components of family-centered care developed under the leadership of the Maternal and Child Health Bureau. These five components were time, listening, sensitivity,

information and partnership. A sixth question regarding interpreter services was included only if applicable. Families that responded “usually” or “always” to the five questions (six if an interpreter was used) were categorized as receiving family-centered care. Covariates in the analysis included severity of the child’s illness, household income, highest household educational attainment, and three variables related to healthcare access (type of insurance, usual source of healthcare, and having a personal physician or nurse). Logistic regression was used to calculate an odds ratio of receiving family-centered care, based on parent report, according to race/ethnicity and household language. Results found that Latino, African American, and children whose race/ethnicity was categorized as “other” had significantly lower adjusted odds of receiving family-centered care compared to White children. Latino children were found to have one-half the odds of receiving family-centered care compared to White children, and African American children had approximately two-thirds the odds compared to White children. Children in households where English was not the primary language also had lower odds of receiving family-centered care compared to households where English was the primary language. With regard to covariates, a significant interaction was found between race/ethnicity and severity of child’s illness, which was measured by parent rating of the impact of the child’s condition on activity. African-American children with severely limiting conditions were just as likely to receive family-centered care as White children, but this pattern was not found for Latino children. The authors concluded that there is only a limited subgroup of children where race/ethnicity did not predict family-centered care (Coker et al., 2010).

Montes and Halterman (2011) conducted a similar study investigating differences in parent reported family-centered care among Black and White children with autism spectrum

disorder (ASD). They used the same data from the 2005-2006 NS-CSHN and the same five indicators of family-centered care as Coker and colleagues (2010). For analyses, the researchers created four categories to examine race and ASD: White children with significant healthcare needs (SHCN) and no ASD, Black children with SHCN and no ASD, White children with ASD, and Black children with ASD. Hispanic ethnicity was treated as a covariate and multi-racial families were not included in the analysis. Results found that having a child with ASD was associated with lower odds of receiving family-centered care on all five indicators. However, parents of Black children with ASD were found to have the highest odds of not receiving family-centered care. The authors discussed the compounding effects of a child being Black and having ASD, and suggested that improvement is needed in providing family-centered care to these children and their families (Montes & Halterman, 2011).

A study by Magana and colleagues (2012) also examined racial and ethnic disparities in quality of healthcare, although their study was not specific to family-centered care. They conducted a comparison of children with autism and children with other developmental disabilities using the 2005-2006 NS-CSHN. In addition to the five family-centered care indicators used by Coker and colleagues (2010) and Montes and Halterman (2011), Magana and colleagues also examined whether or not children had a personal doctor or nurse. Controlling for socioeconomic status, they found that children with autism who were Latino or Black received lower quality healthcare compared to White children. Lower quality care was found for racially and ethnically diverse children with autism compared to children with other developmental disabilities (Magna et al., 2012).

Guerrero and colleagues (2010) used data from the Medical Expenditure Panel Survey (MEPS) and the National Health Interview Survey, collected from 2003 to 2006, to examine racial and ethnic disparities in pediatric family-centered care. They created a composite measure of family-centered care using four questions from the Consumer Assessment of Healthcare Providers and Systems Quality of Care questionnaire. Items asked families to rate how well health providers listened, explained things, showed respect, and spent time with them. Results showed that Latino children had lower odds of receiving all four components of family-centered care compared to White children. Differences in family-centered care between Black and White children were not significant after child characteristics and socioeconomic factors were considered (Guerrero et al., 2010).

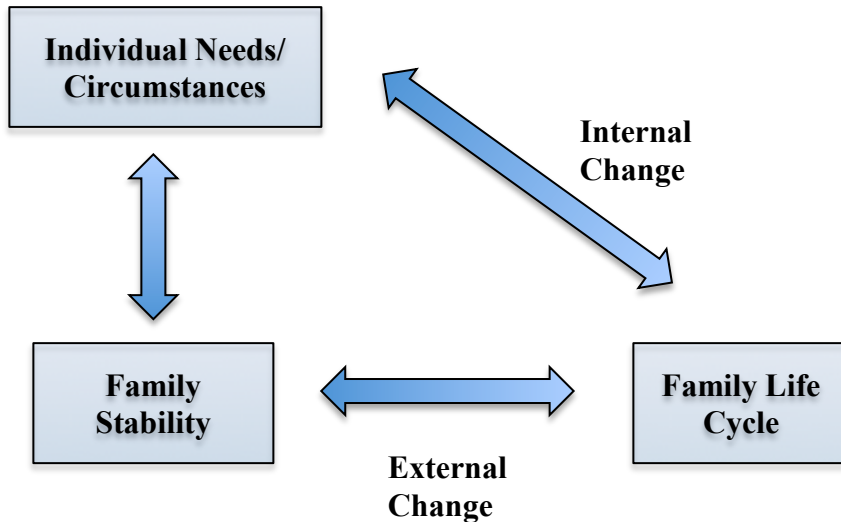
These four reviewed studies comprise the majority of research on ethnic and racial disparities in the provision of family-centered care, which is quite alarming given consistent results showing a clear pattern of ethnic and racial minorities receiving less family-centered care than White families (Coker et al., 2010; Montes & Halterman, 2011; Magna et al., 2012; Guerrero et al., 2010). Researchers of these studies advocate for further investigation of this highly concerning state of healthcare service delivery, and suggest that service providers could benefit from cultural competency training in order to better meet the needs of diverse families. These studies prompt an important question: When racially and ethnically diverse families receive high levels of family-centered care, do they have better outcomes? A study by Ngui and Flores (2006) found disparities in satisfaction with healthcare services between Black and White families of children with special healthcare needs. However, these differences were no longer significant after adjusting for adequacy of family-centered care. While this study appears to be

the only investigation to date examining how family-centered care can potentially improve outcomes experienced by racially and ethnically diverse families, it provides hope that family-centered care may be a key factor in reducing poor healthcare outcomes experienced by these groups.

Relationship between culture and principles of family-centered care. The positive impact of family-centered care on family outcomes can best be understood from the framework of family systems theory. According to family systems theory, the family is an interactional system where the developmental needs and circumstances of each individual member affect the stability of the group (Dore, 2008) (see Figure 1). As families transition through the life cycle, the system must adjust to the changes and development that occur internally within individual members and externally in the family's environment (Dore, 2008). For example, when a child is born with a disability, relationships within the family are likely to change as well as the family's relationship to their community. When healthcare professionals focus on providing services to the whole family instead of solely to the identified patient, they are helping to restore stability within the family system, which in turn enables family members to better support the child. Thus, it is a logical assumption that parents receiving family-centered care are likely to experience increased confidence and success in meeting their child's needs. It also makes sense that family-centered care could facilitate the development of stronger relationships within the family system.

Figure 1

Visual Representation of Family-Systems Theory



Cultural dimensions of family systems theory demonstrate that family dynamics may differ based on culture and ethnicity, indicating that service providers cannot assume that services will be experienced the same way by all families (Dore, 2008). For example, Asian, African American, and Hispanic children are more likely than Caucasian children to live in multigenerational households (Taylor et al., 2011). In order to provide family-centered care in a multigenerational household structure, service providers must consider an expanded version of the family system with an extended parenting subsystem (Dore, 2008). Determining which adults are at the top of the family hierarchy and ensuring that they are supportive and involved in the child's care are critical for successful outcomes (Dore, 2008).

The influence of culture on family dynamics extends far beyond family structure. Research has found that parenting goals, values, and strategies are influenced by ethnic and cultural background, as well historical factors. For example, a study by Julian, McKenry, and

Mckelvey (1994) found that African American mothers highly valued independence and temper control in their children, while African American fathers valued obeying, getting along with others, and succeeding in athletics. These qualities reflect some of the characteristics historically important for the survival of African Americans throughout their history of extreme discrimination and adversity. Hispanic parenting styles have been described in the literature as familial, traditional, and authoritarian, although discrepancies exist in findings (Hill, 2006; Rodriguez & Olswang, 2003). In contrast, European American parenting is often associated with an authoritative parenting style (Steinberg et al., 1992), which focuses on the child's cognitive development as well as social and emotional growth (Chao, 1996). Research has found that acculturation and socioeconomic status influence ethnic groups in different ways, which demonstrates that while there are patterns in parenting styles based on ethnicity and culture, there may be more within-group variation than variation between groups (Rodriguez & Olswang, 2003).

Cultural background also influences how parents interpret their child's development and disability. Rodriguez and Olswang (2003) examined cultural differences in the beliefs of Mexican-American and Anglo-American mothers regarding their child's language impairment. They found that Mexican-American mothers were more likely to endorse external factors to explain their child's impairment, while Anglo-American mothers were more likely to endorse intrinsic factors. Examples of external factors included the home environment, God's will or spirituality, and the match between the home and school environment. Intrinsic factors included family history and heredity, medical conditions, bilingualism, and the child's personality. Yeh and colleagues (2004) conducted a study to examine cultural differences in families' beliefs

about the etiology of their child's emotional and behavioral problems. They found that African American, Asian/Pacific Islander American, and Latino parents were less likely than White parents to endorse a biopsychosocial causal framework to explain their child's problems. African American parents were more likely than Latino parents to endorse a physical cause or prejudice, and Asian Pacific Islander American parents were more likely than all other groups to endorse American culture as an explanatory factor. These results suggest that ethnic minority parents may be more likely to experience dissonance between their own beliefs about the cause of illness and the explanatory models used by Western health care providers. This dissonance can create cultural conflict regarding treatment, which can be eased when health providers take the time to develop culturally informed treatment plans for each patient or family (Campinha-Bacote, 2011).

Given this brief discussion of the impact of culture on parenting practices, beliefs, and values, it is important to examine how family-centered principles, as previously identified, may be interpreted differently by culturally, ethnically, and racially diverse families served in early intervention. Research suggests that families do not universally value family-centered principles or interpret them to have the same meaning (Chao, 1996; Rodriguez & Olswang, 2003). As previously discussed, the basic tenet of family-centered care is the belief that family involvement is integral to the healthy development of the child. However, parents from various cultural backgrounds cultures have different expectations and desires regarding their degree of involvement across the domains of their child's life. Some cultures see their child's upbringing as a collaborative partnership between parents, schools, and the greater community, while other cultures believe in a more divided division of labor (Rodriguez & Olswang, 2003). For example, Rodriguez and Olswang (2003) found that Mexican-American mothers believed that the school

is primarily responsible for educating their children and that parents should not have an active role in this process. Chao (1996) compared Chinese and European American mothers' beliefs about involvement in their child's education and found variations in ideals. He reported that Chinese American mothers valued direct, active involvement in their child's education, with a strong emphasis on parenting practices that increase their child's academic performance. Their families' activities often centered on their child's education, and mothers reported making numerous sacrifices in their own lives in order to provide the attention and time needed to help their child succeed academically. In contrast, while European American mothers also wanted to be actively involved in their child's education, they valued parenting practices that put less of an emphasis on the child's academic performance and a greater emphasis on their child's social and emotional development.

One of the principles of family-centered care, as defined by Kuo and colleagues (2013), is respecting and honoring differences. This seemingly all-inclusive principle might lead service providers to assume that family-centered care is culturally competent by nature. However, Goode and Jones (2006) from the National Center for Cultural Competence suggested that family-centered care might sometimes lack cultural competence in practice. They cited a review by Arango and McPherson (2005), which demonstrated that family-centered care materials, such as articles, books, websites, training manuals, and guides, rarely mention cultural competence. Goode and Jones (2006) explained that family-centered care, cultural competence and linguistic competence are all important approaches in serving families and children with special health care needs, but they do not implicitly overlap. They outlined key components of cultural competence, which extend far beyond respecting and honoring differences. One component requires

organizations to have a defined set of values and principles that enable them to work effectively cross-culturally, and to demonstrate these values and principles in their behaviors, attitudes, policies and structures. A second component requires individuals to value diversity, acquire culture knowledge, perform self-assessments, and adapt to diversity in the communities that they serve. A third component requires an overarching integration of the first two components in policymaking, administration, practice and service delivery. The researchers emphasized that cultural competence evolves over time and should be regarded as a developmental process that exists on a continuum.

Recent research on training therapists has demonstrated a shift from the longstanding focus on cultural competency to a cultural-relational model (Roysircar & Lee-Barber, 2015). Roysircar and Lee-Barber (2015) suggested that it might be unrealistic to expect therapists to develop knowledge of cultural differences that exist within every group they may encounter. Instead, the researchers developed a model highlighting interpersonal engagement as the cornerstone of working with culturally diverse populations, in which therapists must be constantly aware of what is happening in their relationship with their clients. As a result, therapists focus more on developing qualities such as empathy, self-reflexivity and sensitivity, and focus less on acquiring general cultural knowledge, which can lead to stereotyping and poor relationships. Research on racial concordance between health professionals and patients has found evidence to support that patients are more likely to choose providers of the same race or ethnicity, and this concordance is associated with higher patient satisfaction (Lavieist & Nuru-Jeter, 2002). Research also demonstrates that it is easier for people to empathize with those who share their cultural background than with people from another culture (Kohut, 1959). Given this

information, Roysircar and Lee-Barber's model emphasized the importance for therapists to use observation and self-reflection to acknowledge their differences instead of pretending that they do not exist. With understanding of these differences, service providers are better equipped to engage with and meet the needs of diverse families (Roysircar & Lee-Barber, 2015).

Given the literature reviewed on both family-centered care and cultural competence, it is clear that the research community has not reached a consensus about the relationship between these concepts. Both family-centered care and cultural competence are concepts that are inherently subjective in nature, which makes them difficult to measure. For the purposes of this study, family-centered care was conceptualized as an approach that encourages culturally competent care by the nature of its defining principles, but without the assumption that culturally competent care consistently occurs in the process of service delivery. Reflecting back on the principles of family systems theory, it seems that a truly family-centered and culturally competent approach may not involve a standard application of practice principles, but rather an approach where service providers take the time to learn about families' norms, values, and expectations. This information can then be used to develop meaningful service provider-client relationships, and deliver respectful and relevant services that fit within families' existing structure.

Limitations of the Previous Research

The research to-date shows two patterns of concern related to the provision of services to families of racially, culturally, and ethnically diverse children. First, findings from the NEILS demonstrated that families of African American children were significantly more likely to experience less positive outcomes from early intervention services compared to families of

Caucasian children (Bailey et al., 2004). African American and Hispanic children are at an increased risk for poor developmental outcomes, while their families are more likely to have increased financial, psychological and social stressors, which can lead to a reduced quality of life (McLoyd, 1990; Steinberg, Dornbush, & Brown, 1992; Stevenson, Chen, & Uttal, 1990).

Second, although family-centered care has been associated with positive outcomes for children with special healthcare needs, studies have shown that African American, Hispanic and Latino families are significantly less likely to receive family-centered care compared to White families (Coker et al., 2010; Montes & Halterman, 2011; Magna et al., 2012; Guerrero et al., 2010).

The literature reviewed is limited in three distinct ways. First, the quantity of studies examining racially, ethnically, and culturally diverse families' experiences with family-centered care is small. While the pattern documenting less family-centered services for these families is discouraging, most studies showing this pattern have used identical measurements of family-centered care based on parents' responses to five survey items. More research needs to be conducted, possibly with more comprehensive measures of family-centered care, in order to better understand the experiences of diverse families. Second, while early intervention services under Part C of IDEA are intended to be family-centered, previous research has not documented the extent to which families from ethnically diverse backgrounds perceive their services to be family-centered based on a nationally representative sample. Due to the research documenting clear benefits of family-centered care for child and family outcomes, it is especially important to investigate if early intervention services are reported to be family-centered by all recipients, including those most at risk. The third limitation of the reviewed literature is the dearth of research examining family-centered care as potential moderator of poor outcomes experienced

by diverse families of children with special healthcare needs. Only one study has demonstrated that the level of family-centered care may moderate poor outcomes related to healthcare satisfaction for Black families (Ngui & Flores, 2006). Additional studies are needed that examine family-centered care as a predictor of family and child outcomes in order to better understand how service delivery can potentially improve outcomes for racially and ethnically diverse families.

The Present Study

The present study was designed to address limitations of the previous research and address two primary research questions. The first question was: Do African American and Hispanic families report significantly less family-centered care in their early intervention experience compared to Caucasian families? It was predicted that African American and Hispanic families would report significantly less family-centered care than Caucasian families. This hypothesis was based on the existing research by Coker and colleagues (2010) and Montes and Halterman (2011) showing ethnic disparities in family-centered care for families of children with special healthcare needs.

The second primary research question addressed by this study was: Does greater perceived family-centered care during early intervention predict better outcomes for racially/ethnically diverse families and their children? To answer this question, three hypotheses were tested. The first hypothesis was that greater family-centered care predicts African American and Hispanic parents' improved ability to figure out what to do about their child's behavior at the end of early intervention services. Analyses from the NEILS demonstrated that African American and Hispanic families were more likely to report difficulties handling their child's

behavior compared to Caucasian families (Bailey et al., 2004). Given that the NEILS researchers identified parents' difficulties addressing their child's behavior as an area of needed improvement, this study aimed to examine the impact of family-centered care on this parent outcome. The second hypothesis was that greater family-centered care predicts greater perceived impact of early intervention services on African American and Hispanic families. The NEILS researchers identified race/ethnicity as a predictor of lower satisfaction and poorer family outcomes at the end of early intervention services (Scarborough et al., 2004), which is why perceived impact of services on the family was selected as an outcome for this study. The third hypothesis was that greater family-centered care during early intervention predicts fewer African American and Hispanic children identified for special education in kindergarten. Research overwhelmingly demonstrates disproportionality of ethnic minorities in special education services (Zhang, Katsiyannis, Ju, & Roberts, 2014). Given the growing amount of research documenting the association of family-centered care with improvement in child health and quality of life (Dunst & Trivette, 2009; Kuo, Bird, & Tilford, 2011), it was important to examine if family-centered care received during early intervention services can reduce the need for special education services years later, once the child has begun formal schooling.

Method

Participants

This study was a secondary analysis of NEILS data from the 36-month and kindergarten data collection periods. The original NEILS sample was identified using a 3-stage stratified sampling procedure, as described by Bailey and colleagues (2004). In the first stage, 20 states were selected based on the number of children served in early intervention. The states had substantial

variation regarding the primary early intervention agency and whether or not they served children at risk. In the second stage, counties within those states were selected based on the estimated number of children served in Part C programs. Between 3 and 7 counties were selected in each state, which provided a total of 93 counties for data collection. In the third stage of the sampling procedure, children and families were selected within those 93 counties. Families were eligible for participation if their child was less than 31 months of age, entered early intervention for the first time between September 1997 and November 1998, and had an adult in the household that spoke English or Spanish. Families that had more than one child in early intervention enrolled only one child in the study. A total of 4,653 families were invited to participate the study and 3,338 enrolled (71%). A total of 2,758 families participated in the 36-month interview, at the transition out of early intervention services, and a total of 1,581 families participated in both the kindergarten family interview and kindergarten teacher survey. More information on the sampling strategy and weighting procedures used to ensure that the sample represented the national population can be found in the NEILS Methodology Report (Javitz et al., 2002).

Child participant demographic characteristics were weighted to provide national estimates of the families receiving early intervention. The following statistics were based on data from the enrollment interview. Children were between 30 and 46 months of age, with the majority between 36 and 40 months (97%) (Bailey et al., 2004). The most common eligibility condition for children in early intervention was a developmental delay (62%) (Bailey et al., 2004). The majority of child participants were male (60%) (Bailey et al., 2004). Fifty-three percent of child participants were Caucasian, 21 percent were African American, 16 percent

were Hispanic, 4 percent were Asian or Pacific Islander, and 5 percent identified as mixed race or other. No data were available on the respondent's race or ethnicity, only the child's, so although discussions in this paper refer to racially and ethnically diverse families, this information is based solely on the race/ethnicity of the child. It must be noted that there are circumstances where children's race/ethnicity does not match that of their primary caregivers', but it is assumed for the purposes of this study that children and their caregivers share the same race/ethnicity the majority of the time. This study used the same terminology as the NEILS to describe racial and ethnic groups (Caucasian, African American, and Hispanic) for the purpose of consistency.

Based on service records and interview information, it was determined that 61 percent of children received early intervention services from enrollment until 36 months of age when services terminated, 22 percent of children exited before 36 months, 2 percent died while receiving early intervention, and service duration for 15 percent of children could not be determined (Bailey et al., 2004). For the families that exited early intervention before 36 months, 60 percent reported that they were no longer eligible for services, 5 percent reported that they could not get services after relocating, 34 percent reported that they did not want or need services, 2 percent reported that family reasons prevented receipt of services, 4 percent reported a problem regarding their local agency, and 1 percent reported various other barriers to receipt of services (Bailey et al., 2004).

Assessment Instruments

The NEILS 36-month Transition Interview and Kindergarten Interview were conducted with the "the person able to answer questions about the child and the child's program," as

determined at the time of initial contact between NEILS researchers and families (Bailey et al., 2004). The majority of interviewees (81%) were the child's biological mother. Other interviewees identified themselves as the child's adoptive mother (6%), biological father (4%), grandmother (4%), or foster mother (2%) (Bailey et al., 2004). Since 93 percent of respondents were the child's biological or legal parent, NEILS authors referred to respondents as parents in the literature (Bailey et al., 2004). The interviews lasted approximately 40 minutes and were conducted by a trained survey research unit. Interviewers used computer-assisted telephone interviewing, which allowed them to enter responses into the computer and receive the next appropriate question based on the parent's previous response. Questions were designed by the NEILS research team and addressed characteristics of the child and family, early intervention services received, and respondent's perceptions of the impact of early intervention services on their child and family. Most questions were asked using a multiple-choice format. Interviews were conducted in Spanish for 5.5 percent of families (Hebbeler et al., 2007).

The NEILS kindergarten teacher survey contained two distinct sections. The first section was developed to collect data on the child's general education program and academic progress, and the second section was designed to collect data on the child's special education services. The child's teacher completed the survey during the spring of the kindergarten year. The survey was brief in comparison to the family interviews, and were completed and returned by mail. Most questions were multiple choice, and both sections of the survey offered an optional narrative section for teachers' comments. A copy of the family interviews and the teacher survey can be found at www.sri.com/neils/.

Procedures

Deriving the family-centered care variable. The first step in addressing the proposed research questions was creating a new variable called “family centeredness”, which reflects the family-centered principles identified by agencies such as the Maternal and Child Health Bureau and the American Academy of Pediatrics, and as outlined by Kuo and colleagues (2013). To review, these principles are as follows: information sharing, respecting and honoring differences, partnership and collaboration, negotiation, and care in context of family and community. Response items were identified from the NEILS 36-month interview that fit these categories. The principle of negotiation was combined with the principles of partnership and collaboration due to the overlap in questions addressing these domains.

The item that fits under the category of information sharing from the NEILS Interview was as follows: *Overall, how would you rate the help and information your family has received through early intervention?* Items that fit under the category of respecting and honoring differences were as follows: (a) *The early intervention professionals respect the values and cultural background of my family. Do you strongly agree, agree, disagree, or strongly disagree that this sounds like you?* (b) *The early intervention professionals giving services to my family ignored my opinions. Do you strongly agree, agree, disagree, or strongly disagree that this sounds like you?* Items that fit under the category of partnership, collaboration, and negotiation were as follows: (a) *Who came up with the goals or “outcomes” for [child] on [his/her] service plan?* (b) *Who decided on the kinds of services for [child]?* (c) *Who decided on the amount of services for [child]?* (d) *How did you feel about your involvement in the decisions about [child’s] services?* The item that fit under the category of care in the context of family and

community included a question that begin with *Did anyone from the early intervention program help you...* and then a list of fifteen service items follow. Examples of services include *Learn how to play with, talk with, or teach your child*, *Find childcare for [child]*, *Meet basic household needs such as food, clothing, or shelter*. For these items, parents were asked to indicate if the service was received, and if it was not received they were asked to indicate if it was needed.

There were a few important considerations when creating the family-centered care variable from the NEILS data. First, responses were highly skewed across all items, with participants responding in an overwhelmingly positive manner to the selected survey questions. This pattern of response was indicative of overall positive experiences with early intervention, which is critical to note with regard to analyses and data interpretation going forward. Second, the format of questions was not standardized. For example, while one item may ask the respondent if they strongly agree, agree, disagree, or strongly disagree, another item may ask the respondent if they received a service and if that service was needed. To address these issues, an analytic strategy similar to that used by Bailey and colleagues (2004) was followed to categorize families as perceiving family-centered care and not perceiving family-centered care. An item-by-item determination as to what constitutes family-centered care is as follows.

For items regarding levels of agreement (strongly agree, agree, disagree, strongly disagree), any response that affirmed a family-centered value (e.g., agree, strongly agree) was coded as family-centered. Any response that conflicted with a family-centered value (e.g., disagree, strongly disagree) was coded as not family-centered. Care was taken to make sure that negatively worded items were coded accurately (e.g., agree or strongly agree were coded as not family centered, while disagree or strongly disagree were coded as family-centered). For items

asking parents to rate the quality of their services, ratings of “excellent” or “good” were coded as family-centered. Ratings of “fair”, “poor” or “mixed” were coded as not family-centered. For items that ask about who made decisions for the child and family, responses of “mostly your family” and “you and the professionals together” were coded as family-centered. The response “mostly the professionals” was coded as not family-centered. The item that asked families about who came up with goals and outcomes for their service plan was only asked if parents reported being aware of the IFSP. If this question was skipped because parents were not aware of the IFSP, it was coded as not family-centered because it is assumed that it was the service provider’s responsibility to involve the family in creating the IFSP. For the item *How did you feel about your involvement in the decisions about [child’s] services?* the response “were involved about the right amount” was coded as family centered. The responses “wanted to be more involved” and “wanted to be less involved” were coded as not family-centered. For the questions asking about service provision to the family, responses were considered not family-centered if a parent reported not receiving a service and needing it. All other responses were coded as family-centered.

Following the outlined procedure, all responses determined to be not family-centered were scored as a 0, and all responses determined to be family-centered were scored as a 1. The dichotomized scores assigned through this procedure were then averaged to create a score for each of the four family-centered care domains for each participant. The average scores from each domain were then summed to create an index score that ranged from 0-4. An index score of 0 indicated that the average score across all family-centered care domains was 0, meaning that all responses were in the not family-centered category. An index score of 4 indicated that the

average of all family-centered care domains was 1, meaning that all responses were in the family-centered category. The advantage of this procedure was to ensure that all four domains were equally represented in the family-centered care index, regardless of the number of response items that fit into the domain. The full list of questions selected for each family-centered care domain, along with the step-wise scoring procedure, is presented in Table 1.

Table 1

Scoring Procedures for Deriving the Family-Centered Care Domain Score

| FCC Domain | Survey Items | Response options and scoring (0= Less FCC, 1= More FCC) | Deriving FCC Domain Score |
|---|---|--|--------------------------------------|
| Information Sharing | <i>1. Overall, how would you rate the help and information your family has received through early intervention?</i> | Excellent=1 Good=1 Fair=0 Poor=0 Some OK, some not=0 | Score from question 1 |
| Respecting and Honoring Differences | <i>2. The early intervention professionals respect the values and cultural background of my family.</i> | Strongly agree =1 Agree=1 Disagree=0 Strongly disagree=0 | Average of scores from questions 2-3 |
| | <i>3. The early intervention professionals giving services to my family ignored my opinions.</i> | Strongly agree=0 Agree=0 Disagree=1 Strongly disagree=1 | |
| Partnership, Collaboration, and Negotiation | <i>4. Who came up with the goals or “outcomes” for [child] on [his/her] service plan?</i> | Not aware of IFSP=0 Mostly family=1 Mostly professionals=0 Both family and professionals =1 | Average of scores from questions 4-7 |
| | <i>5. Who decided on the kinds of services for [child]?</i> | Mostly family=1 Mostly professionals=0 Both family and | |

| | | | |
|---|--|---|---------------------------------------|
| | | professionals=1 | |
| | 6. <i>Who decided on the amount of services for [child]?</i> | Mostly family=1 Mostly professionals=0 Both family and professionals=1 | |
| | 7. <i>How did you feel about your involvement in the decisions about [child's] services?</i> | Wanted more involvement=0 Involved the right amount=1 Wanted less involvement=0 | |
| Care in Context of Family and Community | 8. <i>Did anyone from the early intervention program help you understand child's development or special needs?</i> | Yes, received=1 No, did need=0 No, didn't need=1 | Average of scores from questions 8-22 |
| | 9. <i>Did anyone from the early intervention program help you learn how to play with, talk with, or teach your child?</i> | Yes, received=1 No, did need=0 No, didn't need=1 | |
| | 10. <i>Did anyone from the early intervention program help you find and/or pay for special equipment, toys or therapy?</i> | Yes, received=1 No, did need=0 No, didn't need=1 | |
| | 11. <i>Did anyone from the early intervention program help you find and/or pay for respite care?</i> | Yes, received=1 No, did need=0 No, didn't need=1 | |
| | 12. <i>Did anyone from the early intervention program help you find info about recreation activity?</i> | Yes, received=1 No, did need=0 No, didn't need=1 | |
| | 13. <i>Did anyone from the early intervention program help you get transportation for child?</i> | Yes, received=1 No, did need=0 No, didn't need=1 | |

| | |
|---|--|
| <i>14. Did anyone from the early intervention program help you find childcare for child?</i> | Yes, received=1 No, did need=0 No, didn't need=1 |
| <i>15. Did anyone from the early intervention program help you find and/or pay for medical or dental services?</i> | Yes, received=1 No, did need=0 No, didn't need=1 |
| <i>16. Did anyone from the early intervention program help you find other agencies and services?</i> | Yes, received=1 No, did need=0 No, didn't need=1 |
| <i>17. Did anyone from the early intervention program help you understand legal rights and protections?</i> | Yes, received=1 No, did need=0 No, didn't need=1 |
| <i>18. Did anyone from the early intervention program help you include child in family routine?</i> | Yes, received=1 No, did need=0 No, didn't need=1 |
| <i>19. Did anyone from the early intervention program help you find or talk with other families of children with special needs?</i> | Yes, received=1 No, did need=0 No, didn't need=1 |
| <i>20. Did anyone from the early intervention program help you find a counselor, minister, or other helper?</i> | Yes, received=1 No, did need=0 No, didn't need=1 |
| <i>21. Did anyone from the early intervention program help you meet basic household needs?</i> | Yes, received=1 No, did need=0 No, didn't need=1 |
| <i>22. Did anyone from the early intervention program help you with solutions to other problems?</i> | Yes, received=1 No, did need=0 No, didn't need=1 |

The final step in creating the family-centered care variable was to assign participants to groups based on family-centered care index score. Continuing to follow the conventions of Bailey and colleagues (2004), arbitrary cut-offs were used to determine group membership. Unlike Bailey and colleagues (2004), participants were assigned to three groups instead of two groups in order to retain some degree of variability in responses. Participants with an index score from 0 through 3.49 were assigned to the “Less FCC” group, participants with an index score from 3.50 through 3.99 were assigned to the “Moderate FCC” group, and participants with an index score of 4 were assigned to the “High FCC” group. It must be noted that the cut-offs for the family-centered care categories were towards the upper limits in the range of possible family-centered care scores. There were several reasons for these cutoffs. First, the responses to the selected survey items were skewed in the direction of high family-centered care. If cut-offs had been lower, there would have been problems with small cell sizes in analyses. Second, it is believed that the variability within the high-end of the range of scores is meaningful. Due to the overwhelming proportion of respondents who perceived high levels of family-centered care, it was especially notable when families responded to an item in a way that was inconsistent with family-centered care. Families’ responses may have been impacted by social desirability or other factors that were beyond this study’s control. Thus, the cut-offs appear to be reasonable given the distribution of the data, and capture variability that is meaningful with regard to families’ experiences in early intervention.

Demographic variables. Additional demographic variables included in all analyses were child health status, household income, and mother’s education. Child health status was originally rated on the following scale: 1= Excellent, 2= Very good, 3=Good, 4=Fair, 5=Poor. The scale

was reversed for ease of data interpretation, and condensed into fewer categories due to small cell count. The new categories were as follows: 1= Poor/fair, 2= Good/Very Good, 3= Excellent. Household income was originally rated based on 24 income categories, and was consolidated for the purposes of this study into the following four categories: 1= 25,000 or less, 2= 25,001 – 50,000, 3= 50,001-75,000, 4= >75,000. Mother's education was determined based on the highest level of education attained by the child's primary female caregiver at the time of data collection. It was originally rated based on the following seven categories: 1= Less than high school diploma, 2= High school diploma/GED, 3= Some college or vocational school, 4= 2-3 year degree or diploma, 5= 4-year college degree, 6= Some graduate school, 7=Graduate degree. Responses were collapsed into the following categories due to small cell count: 1= High school diploma/GED or less, 2= Some college, 3= Four-year college degree and beyond. For analyses of outcomes at the end of early intervention, demographic data from the 36-month Family Interview were utilized. For analyses of kindergarten outcomes, demographic data from the Kindergarten Family Interview and the Kindergarten Teacher Survey were utilized.

Data Analysis

All analyses were completed using the Complex Samples Module of SPSS Statistics 22. Descriptive statistics for family centered-care score, child health, household income, and highest level of education achieved by the child's primary female caregiver were calculated to examine characteristics of the data. Ordinal regression was used to address research question one, and logistic regressions were used to address questions two, three, and four. Odds ratios were calculated for all variables that made significant contributions to the model. Analyses were performed under the assumption of proportional odds. The Sequential Bonferroni correction was

applied in each analysis to adjust for multiple tests. Appropriate weights for each analysis were applied as indicated by Javitz and colleagues (2002).

To test the first hypothesis, which addressed differences in family-centered care by race/ethnicity, the dependent variable was family-centered care group membership. Independent variables were the child's race/ethnicity (African American, Hispanic, or Caucasian), as reported during the NEILS enrollment interview, child's health status, household income, and maternal education. To test the second hypothesis, which addressed family-centered care as a predictor of respondents' ability to handle the child's behaviors at the termination of early intervention services, the dependent variable was respondents' answer to the statement: *I often have a difficult time figuring out what to do about my child's behavior*. Original responses were "Strongly agree" "Agree", "Disagree", and "Strongly disagree", but were changed to a dichotomous outcome for the purposes of this analysis. "Strongly agree" and "Agree" were collapsed into the category "Agree", and "Disagree" and "Strongly disagree" were collapsed into the category "Disagree". The purpose of converting responses to a dichotomous outcome variable was due to small cell count. The independent variables were family-centered care group membership, child's health status, household income, and maternal education. Separate logistic regressions were calculated for African American and Hispanic families. For the third hypothesis, which addressed family-centered care as a predictor of perceived impact of early intervention services on the family, the dependent variable was respondents' answer to the statement: *Thinking about the whole time you have received services, how has the help and information you received affected your family? Do you think your family is....*. Original responses were: "Worse off," "About the same", "Somewhat better off", "Much better off" and "Too soon to tell". Responses

were collapsed into dichotomous responses of “Worse off/About the same” and “Somewhat/much better off” for the purposes of this analysis. Families that responded “Too soon to tell” were not included in the analysis. The purpose of converting responses to a dichotomous outcome variable was again due to small cell count. The independent variables in this analysis were family-centered care group membership, child’s health status, household income, and maternal education. Separate ordered logistic regressions were calculated for African American and Hispanic families. To address the fourth hypothesis, regarding family-centered care as a predictor of kindergarten special education status, data from the Kindergarten Family Interview and the Kindergarten Teacher Survey were utilized. The dependent variable was the dichotomous outcome of child’s special education status, specifically “IEP” or “No IEP”, as reported by the child’s teacher. The independent variables were family-centered care group membership, child’s health status, household income, and maternal education. Separate logistic regressions were calculated for African American and Hispanic families. Table 2 outlines each hypothesis, and the respective variables and weights that were used to test each hypothesis. Table 3 provides additional information regarding the scoring of each variable and the data collection period during which the variable was derived.

Table 2

Hypotheses, Variables, and Weights

| Hypotheses | Independent Variables | Dependent Variables | Weight Utilized |
|---|---|---|--------------------------------------|
| African American and Hispanic families will report significantly less family-centered care than Caucasian families. | Child's Race/Ethnicity Household Income Maternal Education Child Health Status | FCC | 36-Month Transition Family Interview |
| Greater family-centered will predict African American and Hispanic parents' improved ability to figure out what to do about their child's behavior at the end of early intervention services. | FCC Household Income Maternal Education Child Health Status | Reported difficulty addressing child's behavior | 36-Month Transition Family Interview |
| Greater family-centered care will predict greater perceived impact of early intervention services on African American and Hispanic families. | FCC Household Income Maternal Education Child Health Status | Reported impact of early intervention on the family | 36-Month Transition Family Interview |
| Greater family-centered care during intervention will predict fewer African and American and Hispanic children identified for special education in kindergarten. | FCC Household Income Maternal Education Child Health Status | Kindergarten IEP Status | Kindergarten Teacher Interview |

Table 3

Descriptions of Variables

| Variable | Levels of Variable used in Analysis | Data Collection Period for Variables used in Analyses |
|---|---|---|
| Child's Race/Ethnicity | White, Hispanic, African American | Enrollment Interview |
| Household Income | 1= 25,000 or less, 2= 25,001 – 50,000, 3= 50,001-75,000, 4= >75,000 | Transition Family Interview and Kindergarten Family Interview |
| Maternal Education | 1= High school diploma/GED or less, 2= Some college, 3= Four-year college degree and beyond | Transition Family Interview and Kindergarten Family Interview |
| Child Health Status | 1= Poor/fair, 2= Good/Very Good, 3= Excellent | Transition Family Interview and Kindergarten Family Interview |
| Family-Centered Care | Less FCC, Moderate FCC, High FCC | Transition Family Interview |
| Reported difficulty addressing child's behavior | Agree/Disagree | Transition Family Interview |
| Reported impact of early intervention on the family | Worse off/About the same and Somewhat/much better off | Transition Family Interview |
| Kindergarten IEP Status | IEP/No IEP | Kindergarten Teacher Interview |

Results**Descriptive Statistics**

Weighted population estimates are presented by percentages for race/ethnicity, mother's education, household income, and child health in Table 4. Demographics in Table 4 are based on participants enrolled in NEILS at the 36-month Transition Interview data collection period. Data

on race/ethnicity were collected during the Enrollment Family Interview. All other data were collected during the 36-month Transition Interview.

Table 4

Weighted Population Estimates of Demographic Characteristics of NEILS Child Participants from the 36-Month Transition Interview Data Collection Point

| Characteristics | Percentage |
|--|------------|
| Child's Race/Ethnicity | |
| Caucasian | 54.2 (2.5) |
| African American | 20.7 (1.8) |
| Hispanic | 15.8 (2.6) |
| Asian/Native Hawaiian/ Pacific Islander | 3.8 (1.8) |
| American Indian / Alaskan Native | 0.5 (0.2) |
| Other/Multiple | 5.0 (1.0) |
| Mother's education level | |
| High school diploma or less | 44.9 (1.7) |
| Some college | 28.3 (1.1) |
| Four-year college and beyond | 26.8 (1.1) |
| Household Income | |
| 25,000 or less | 36.3 (2.0) |
| 25,001 to 50,000 | 27.6 (1.4) |
| 50,0001 to 75,000 | 20.0 (1.1) |
| > 75,0001 | 16.1 (1.4) |
| Child Health Status | |
| Poor/Fair | 12.7 (0.7) |
| Good/Very Good | 47.9 (1.4) |
| Excellent | 39.5 (1.8) |

Note: Analysis utilized weights from the 36-Month Transition Interview data collection point. Values are in percentages and describe a nationally representative weighted sample. Values may not add to 100 because of rounding and/or missing data.

Population estimates of demographic data, including mother's education, household income, and child health status are presented in percentages in Table 5. Columns in Table 5 show

population estimates based on participants enrolled in NEILS at the 36-month Transition Interview data collection period. Results found similar population estimates across demographic variables for African American and Hispanic families, while population estimates for Caucasian families followed a different pattern. For child health status, population estimates showed African American and Hispanic families with more children in the “Poor/Fair” health category compared to Caucasian families. Hispanic families had more children in the “Excellent” category than African American families, but Caucasian families had the highest percentage in the “Excellent” category across racial/ethnic groups. With regard to household income, population estimates found African American and Hispanic families to have the highest percentages in the lowest income category, “25,000 or less” and the lowest percentage of responses in the highest income category, “>75,000.” Population estimates for Caucasian families showed the lowest percentage of families in the lowest income category, “25,000 or less”, and a similar distribution of families across the middle and highest income categories. For maternal education, population estimates showed that more than half of mothers of African American and Hispanic children had achieved a high school diploma or less, while more than half of mothers of Caucasian children had achieved a minimum of some college education.

Table 5

Weighted Population Estimates of Demographic Characteristics of NEILS Child Participants by Race/Ethnicity from the 36-Month Transition Interview Data Collection Point

| Demographic Variable | Race/Ethnicity | | |
|-----------------------------------|----------------|------------|------------|
| | AA | Hispanic | Caucasian |
| Child Health | | | |
| Poor/Fair | 16.7 (1.5) | 20.6 (1.8) | 9.0 (0.8) |
| Good/Very Good | 54.8 (3.0) | 44.0 (3.8) | 46.4 (2.0) |
| Excellent | 28.5 (2.5) | 35.4 (3.6) | 44.6 (2.5) |
| Household Income | | | |
| 25,000 or less | 62.3 (2.5) | 55.1 (3.1) | 21.7 (2.9) |
| 25,001-\$50,000 | 25.3 (2.1) | 24.4 (1.8) | 29.7 (2.2) |
| 50,001-\$75,000 | 7.6 (0.9) | 14.2 (2.2) | 26.6 (1.4) |
| > 75,000 | 4.8 (1.6) | 6.3 (1.3) | 22.0 (2.2) |
| Mother's Education | | | |
| High school diploma or less | 60.2 (2.6) | 62.8 (3.4) | 34.4 (2.3) |
| Some college or vocational school | 29.0 (2.4) | 22.1 (2.1) | 30.7 (1.7) |
| 4-year college degree or beyond | 10.8 (1.5) | 15.1 (2.3) | 34.9 (1.5) |

Note: Analysis utilized weights from the 36-Month Transition Interview data collection point. Values are in percentages and describe a nationally representative weighted sample. Values may not add to 100 because of rounding and/or missing data.

Means of family-centered care domain are presented by race/ethnicity in Table 6. These means are based on the 36-month Transition Interview data collection point. Results show means near the upper limit of possible values, which range from 0 to 1, but consistently lower means for the Partnership, Collaboration, and Negotiation domain compared to the other domains across racial/ethnic groups. Further investigation of the responses to questions in this domain showed that nearly 38 percent of respondents reported that “mostly the professionals” decided on the amount of services for their family. With regard to the other items in this domain, respondents

gave a non-family-centered response between 15 and 18 percent of the time. Hispanic families reported less family centered responses with regard to who determined the goals (26.8%), amount of service (48.1%), and kinds of services (23%), while African American families reported less family-centered responses regarding their overall involvement in decisions about services (29.6%). Respecting and Honoring Differences consistently yielded the highest means across all racial/ethnic groups compared to the other domains. Caucasian families had higher means than African American and Hispanic families across all family-centered care domains.

Table 6

Weighted Population Estimates of Mean Family-Centered Care (FCC) Domains by Race/Ethnicity from the 36-Month Transition Interview Data Collection Point

| FCC Domain | Race/Ethnicity | | |
|---|----------------|-----------|-----------|
| | AA | Hispanic | Caucasian |
| Information Sharing | .84 (.02) | .88 (.02) | .92 (.01) |
| Respecting and Honoring Differences | .93 (.01) | .94 (.01) | .96 (.00) |
| Partnership, Collaboration, and Negotiation | .74 (.02) | .70 (.02) | .83 (.01) |
| Care in Context of Family and Community | .86 (.01) | .88 (.01) | .95 (.00) |

Note: Analysis utilized weights from the 36-Month Transition Interview data collection point.

Table 7 presents population estimates by percentages for family-centered care group membership based on the 36-month Transition Interview data collection point. A clear pattern is evident regarding family-centered care by racial/ethnic group. Caucasian families had a higher percentage in the “High FCC” group compared to the “Less FCC” group. The opposite pattern was seen for Hispanic and African American families, with higher percentages in the “Less FCC” group than the “High FCC” group.

Table 7

Family-Centered Care Population Estimates by Race/Ethnicity from the 36-Month Transition Interview Data Collection Point

| Race/Ethnicity | FCC Group | | |
|----------------|------------|--------------|------------|
| | Less FCC | Moderate FCC | High FCC |
| AA | 37.8 (2.9) | 38.0 (2.8) | 24.2 (3.1) |
| Hispanic | 36.8 (3.4) | 40.9 (2.7) | 22.3 (3.5) |
| Caucasian | 18.6 (1.3) | 41.4 (2.3) | 40.0 (3.3) |

Note: Analysis utilized weights from the 36-Month Transition Interview data collection point. Values are in percentages and describe a nationally representative weighted sample. Values may not add to 100 because of rounding and/or missing data.

Family-Centered Care as a Predictor of Race/Ethnicity

First, the hypothesis that race/ethnicity would significantly predict perceived family-centered care was tested using ordinal regression. The dependent variable was family-centered care, and the independent variables were child's race/ethnicity, household income, maternal education, and child health status. Results revealed that race/ethnicity was a significant predictor of family-centered care group membership ($F[3, 17] = 15.094, p < .001$), which supported the first hypothesis. The odds of being in the "Less FCC" group for families of African American children were 1.905 (95% CI, 1.501 to 2.419) compared to families of Caucasian children. The odds of being in the "Less FCC" group for families of Hispanic children were 2.012 (95% CI, 1.481 to 2.733) compared to families of Caucasian children. Household income was also a significant predictor of family-centered care group membership ($F[3, 17] = 15.404, p < .005$). The odds of being in the "Less FCC" group were 1.548 (95% CI, 1.247 to 1.923) for families who earn 25,000 or less compared to families that earn more than 75,000. Child health status was also

a significant predictor of family-centered care group membership ($F[2, 18]= 4.075, p<.05$). The odds of being in the “Less FCC” group were 1.528 (95% CI, 1.080 to 2.161) for families of children in poor or fair health compared to families of children in excellent health. The odds of being in the “Less FCC” group were 1.247 (95% CI, .990 to 1.570) for families of children in good or very good health compared to families of children in excellent health. Maternal education did not significantly contribute to the model ($F[2,18]= 2.881, p=.668$). The model predicted 42.6 percent of the responses correctly.

Family-Centered Care as a Predictor of Early Intervention Outcomes

Family-centered care as a predictor of parents’ reported ability to address child’s behavior. Next, logistic regression was used to test the hypothesis that greater family-centered predicts African American and Hispanic parents’ ability to figure out what to do about their child’s behavior at the end of early intervention services. The dependent variable was parents’ reported difficulty addressing their child’s behavior, and the independent variables were family-centered care, household income, maternal education, and child health status. This hypothesis was not supported. For families of African American children, family-centered care group membership was not a significant predictor of parents’ reported difficulty figuring out what to do about their child’s behavior at the end of early intervention services ($F[2, 18]= 2.575, p=.080$). Child health status was a significant predictor of parents’ reported difficulty figuring out what to do about their child’s behavior ($F[2, 18]= 10.182, p<.01$). The odds of parents having a difficult time figuring what to do about the child’s behavior were 3.094 (95% CI, 1.533 to 6.248) for children in poor or fair health compared to children in excellent health. Maternal education was also a significant predictor of parents’ reported difficulty figuring out what to do about their

child's behavior ($F[2, 18] = 5.372, p < .05$). The odds of having a difficult time figuring what to do about the child's behavior were 2.896 (95% CI, 1.249 to 6.715) for families with mothers who had a high school education or less compared to families with mothers who had a 4-year college degree or beyond. Household income did not significantly contribute to the model ($F[3, 17] = .693, p = 1.00$). The model predicted 67.7 percent of the responses correctly.

For families of Hispanic children, family-centered care group membership was also not a significant predictor of parents' reported difficulty figuring out what to do about their child's behavior at the end of early intervention services ($F[2, 18] = 1.935, p = .178$). Household income was a significant predictor of parents' reported difficulty figuring out what to do about their child's behavior after the adjustment for multiple comparisons ($F[3, 17] = 3.071, p < .05$). The odds of having a difficult time figuring what to do about the child's behavior were 4.696 (95% CI, 1.387 to 15.901) for families with an income of 25,000 or less compared to families with an income over 75,000. Maternal education ($F[2, 18] = .078, p = 1.00$) and child health status ($F[2, 18] = 2.486, p = .067$) did not significantly contribute to the model. The model predicted 58.5 percent of the responses correctly.

Family-centered care as a predictor of parents' perceived impact of early intervention on the family. For the next analysis, logistic regression was used to test the hypothesis that greater family-centered care predicts greater perceived impact of early intervention services on African American and Hispanic families. The dependent variable was parents' reported impact of early intervention services on their family, and the independent variables were family-centered care, household income, maternal education, and child health status. This hypothesis was partially supported. For families of African American children,

family-centered care group membership was a significant predictor of perceived impact of early intervention services on the family ($F[4, 16] = 61.337, p < .01$). The odds of reporting that the family was much or somewhat better off at the end of early intervention services were .199 (95% CI, .061 to .646) for families in the “Less FCC” group compared to families in the “High FCC” group. The odds of reporting that the family was much or somewhat better off at the end of early intervention services were .791 (95% CI, .308 to 2.028) for families in the “Moderate FCC” group compared to families in the “High FCC” group. Child health status was also a significant predictor of perceived impact of early intervention on the family ($F[3, 17] = 559.113, p < .001$). The odds of reporting that the family was better off at the end of early intervention were 2.641 (95% CI, .871 to 8.009) for families of children in the “Poor/Fair” health group compared to families of children in the “Excellent” health group. Household income ($F[5, 15] = 2.197, p = 1.000$) and maternal education ($F[2, 18] = 1.466, p = .655$) did not significantly contribute to the model. The model predicted 71.0 percent of the responses correctly.

For families of Hispanic children, family-centered care group membership was not a significant predictor of perceived impact of early intervention services on the family ($F[2, 18] = .616, p = 1.000$). Household income ($F[3, 17] = .719, p = .939$), child health status ($F[2, 18] = 1.108, p = .701$), and maternal education ($F[2, 18] = .331, p = 1.000$) did not significantly contribute to the model.

Family-Centered Care as a Predictor of Kindergarten Special Education Status

Finally, logistic regression was used to test the hypothesis that greater family-centered care during early intervention would predict fewer African and American and Hispanic children identified for special education in kindergarten. The dependent variable was kindergarten

Individualized Education Program (IEP) status, and the independent variables were family-centered care, household income, maternal education, and child health status. This hypothesis was partially supported. For African American children, family-centered care group membership was not a significant predictor of kindergarten special education status ($F[2, 18] = .389, p = .949$). Household income ($F[3, 17] = 2.142, p = .660$), maternal education ($F[2, 18] = .046, p = 1.000$), and child health status ($F[2, 18] = 2.677, p = .057$) at the time of kindergarten did not significantly contribute to the model.

For Hispanic children, family-centered care group membership was a significant predictor of kindergarten special education status ($F[2, 18] = .3.787, p < .05$). The odds of having an IEP in kindergarten were 2.487 (95% CI, .635 to 9.740) for children from families in the “Less FCC” group compared to the “High FCC” group. The odds of having an IEP in kindergarten were 4.218 (95% CI, 1.409 to 12.631) for children from families in the “Moderate FCC” group compared to the “High FCC” group. Household income ($F[3, 17] = .443, p = .752$), maternal education ($F[2, 18] = .878, p = 1.000$), and child health status ($F[2, 18] = 2.079, p = .203$) at the time of kindergarten did not significantly contribute to the model. The model predicted 59.5 percent of the responses correctly.

Discussion

The aim of this study was to address two primary research questions: (a) Is race/ethnicity a significant predictor of perceived family-centered care? (b) Does greater perceived family-centered care during early intervention predict better outcomes for racially/ethnically diverse families and their children? Overall, results provided support for the hypothesis that race/ethnicity was a significant predictor of reported family-centered care. Parents of Caucasian

children were more likely to report high levels of family-centered care compared to parents of African American and Hispanic children. Household income and child health status also predicted reported family-centered care, with higher household income and better child health associated with reported higher levels of family-centered care. These findings add to the small pool of studies that have examined the relationship between race/ethnicity and family-centered care. These results are in accordance with the findings of Coker, Rodriguez and Flores (2010), and Montes and Halterman (2011) who also found a discrepancy between reported family-centered care of Caucasian and ethnic minority families.

Results also indicated that family-centered care was a predictor of some child and family outcomes for African American and Hispanic families. Family-centered care was not a significant predictor of parents' reported difficulty figuring out what to do about their child's behavior at the end of early intervention services for families of African American or Hispanic children. For families of African American children, child health status and maternal education were significant predictors of parents' reported difficulty figuring out what to do about their child's behavior, with worse child health and lower maternal education associated with more difficulty with addressing the child's behaviors. For families of Hispanic children, household income was a significant predictor of parents' reported difficulty figuring out what to do about their child's behavior, with lower income associated with more difficulty with addressing the child's behaviors. Child health status and maternal education were not significant predictors for Hispanic families, as they were for African American families. Family-centered care was a significant predictor of perceived impact of early intervention services on the families of African American children, but not for families of Hispanic children. Child health status was a significant

predictor of perceived impact of early intervention services for families of African American children, with worse child health predicting greater impact of services on the family. This relationship was not found for families of Hispanic children. Maternal education and household income were not significant predictors of perceived impact of early intervention services on the family for either group. Family-centered care was a predictor of kindergarten special education status for Hispanic children, with higher family-centered care related to lower odds of having an IEP, but not for African American children. Child health status, household income, and maternal education did not predict special education status for Hispanic or African American children. Although family-centered care was not found to be a predictor of all outcomes measured in this study, findings suggest that family-centered care matters in enhancing early intervention outcomes for racially and ethnically diverse families.

Findings from this study have important implications for parents, educators, early education specialists, health care providers, psychologists, and policy makers. First, these findings provide additional support for the idea that family-centered care in early intervention may not be experienced equally across racial and ethnic groups. Given the growing amount of research documenting the association of family-centered care with improvement in child health and quality of life (Dunst & Trivette, 2009; Kuo, Bird, & Tilford, 2011) as well as improvement in family functioning, satisfaction with services and access to care (Kuhlthau et al., 2011), the notation of discrepant experiences of family-centered care by race/ethnicity in early intervention services is concerning, and should be considered an area of needed improvement. Although there is evidence that early intervention services may help to close the achievement gap for racial/ethnic minorities (Perez-Johnson & Maynard, 2007), it is possible that early intervention

could have an even greater impact if racial and ethnic minority families experienced the same level of family-centered care as Caucasian families.

These results also have important implications for school psychologists, who often work closely with the children and families who previously received early intervention services. It is important for them to consider that African American and Hispanic families perceive early intervention services as less family-centered than Caucasian families, which may lead to different expectations about their involvement in their child's education at the elementary, middle, and high school levels. It is critical that school psychologists reach out to families of all backgrounds to encourage their involvement, but also to understand cultural differences in how much involvement is desired by families. School psychologists may also have an active role in providing or overseeing early intervention services. In these circumstances, it is important that they understand how family-centered care can make a difference in early intervention outcomes for children and families of diverse backgrounds, and implement family-centered practices in their work.

It is important to consider that the majority of early intervention services professionals in the NEILS were Caucasian, highly educated, and unlikely to speak another language (Hebbeler et al., 2007). As previously reviewed, research on racial concordance between health professionals and patients has found evidence to support that patients are more likely to choose providers of the same race or ethnicity, and this concordance is associated with higher patient satisfaction (Lavieist & Nuru-Jeter, 2002). Research also demonstrates that it is easier for people to empathize with those who share their cultural background than with people from another culture (Kohut, 1959). However, racial concordance may not necessarily be associated with

better health outcomes for minority families (Meghani et al., 2009). In the present study, it is possible that racial, ethnic, or cultural concordance, or lack of concordance, played a role in how parents responded to the questions that contributed to the family-centered care index. It is also vital to consider the degree of cultural competency of the early intervention service providers working with families of African American and Hispanic children. Although the NEILS service providers were described as highly educated, no information about their degree of cultural competency was indicated. If cultural competency was assessed, the connection between cultural competencies of service providers and family-centered could be better understood. It is important for service providers and policy makers to better understand this relationship to make empirically driven recommendations for the future of early intervention services.

The relationship between reported family-centered care at the end of early intervention and special education status in kindergarten is particularly notable, due to the approximate two-year period that spans from the exit of early intervention services to entry into kindergarten. For Hispanic children, family-centered care was the only predictive variable for kindergarten special education status included in the model, with families in the “Less FCC” group having greater odds of having an IEP in kindergarten than families in the “High FCC” group. These results suggest that the impact of perceived family-centered care during early intervention services may continue to impact the child years after services are terminated, specifically for Hispanic children. It must be noted, however, that this study does not fully capture the relationship between family-centered care and special education status, as children who did not have an IEP in kindergarten may have qualified for an IEP later in school.

The results of this study highlight differences in the impact of perceived family-centered care on early intervention outcomes for African American and Hispanic families. For African American families, perceived family-centered care was found to be a predictor of perceived impact of early intervention services on the family, but this association was not found for Hispanic families. Child health status was a significant predictor of perceived impact of early intervention services for African American families, but again this association was not found for Hispanic families. For Hispanic families, perceived family-centered care was found to be a predictor of kindergarten special education status, but this association was not found for African American families. These results highlight the importance of examining how cultural expectations, values, and norms of different racial/ethnic groups interact with perceptions of family centered care, and how these impact short and long term child and family outcomes. In addition, these results highlight the importance of not over-generalizing early intervention outcomes and family-centered care effects across racial/ethnic minority groups. These results suggest that there is something unique about being in the African American group or the Hispanic group with regard to early intervention outcomes and perceptions of family centered care, and these differences must be carefully considered before making conclusions regarding the overarching experiences of racial/ethnic minority families.

These results also underscore the connection between children's health status, family-centered care, and early intervention outcomes. Families of children in excellent health reported higher family-centered care than families of children in poor health. In addition, families of children in poor/fair health were much more likely to be African American or Hispanic than Caucasian. These results are discouraging, as child health status implies information about level

of the child's impairment and level of need. It is possible that families of children in poor health are receiving less family-centered care, but it is also possible that children in poor health make fewer developmental gains than children in excellent health, which colors the family's perception of services. These results emphasize the importance of providing access to high-quality healthcare to young children and their families of all backgrounds in hopes of achieving better health outcomes. A notable finding was the relationship between poor child health and higher perceived impact of early intervention services for African American families. Further analysis examining the relationship between racial/ethnic group, family-centered care and child health status would be helpful to better understand these results.

This study had several limitations. First, while input from authoritative bodies such as the Child and Maternal Health Bureau and American Academy of Pediatrics informed the construction of the family-centered care variable, it is still considered to be a subjective conceptual interpretation. It is likely that parents' assessment of family-centered care was closely related to their satisfaction, and it is difficult to determine if the survey items selected for the family-centered care variable differed from assessments of pure satisfaction in subtle but important ways. The survey items used to construct the family-centered care variable were limited to the items used in the original NEILS survey, which posed challenges because the NEILS researchers did not construct items with the intention of assessing family-centered care. In addition, the family-centered variable was entirely based on parent self-report, which further adds to its subjective nature.

A second limitation was related to the non-normal distribution of families' responses to the family-centered variables. This distribution posed challenges for analysis, and required the

use of arbitrary cut-points to determine group categories. Families reported overwhelmingly high levels of perceived family-centered care in early intervention services, which is excellent news for early intervention programming as a whole. In order to avoid ending up with zero participants in any cell for analysis, the cut-point for the “Less FCC” group needed to be near the maximum value in the range of possible family-centered care index scores. This analytical strategy indicates that the results of this study must be interpreted with caution. The “Less FCC” group did not report low levels of family-centered care; they simply reported less family-centered care than the moderate and high groups. This distinction is especially important when drawing conclusions about the patterns of perceived family-centered care for African American and Hispanic families in this study.

Third, when families did report less family-centered care, they were likely to report non-family-centered responses to the items in the Partnership, Collaboration, and Negotiation domain. These survey items inquired about who set the goals for the Individualized Family Service Plan, who decided on the kinds of services, and who determined the amount of services that the family received. Families were especially likely to say that they did not have a role in determining the amount of services. It can be argued that even within family-centered service delivery, there are some limitations to how much the family can be involved in decision making when it comes to federally funded programs. It is possible that this question regarding the amount of services received was not assessing a realistic goal of family-centered care in early intervention.

A fourth limitation of this study was the presence of small cell sizes for some analyses. Instead of analyzing the full range of responses to items to calculate the family-centered care

domain score, response categories had to be collapsed into dichotomous categories of “family-centered” and “not family-centered.” Response categories in outcome questions about parents’ ability to handle their child’s behaviors and perceived impact of early intervention services on the family were also collapsed. The decision to collapse response categories resulted in reduced variability in outcomes, which prevented further understanding of how subtle gradations in responses impacted perception of family-centered care.

A fifth limitation of the study was related to the variables used in analyses. While race/ethnicity and household income were included as variables in all analyses, no analysis examined the experiences of different racial/ethnic groups within specific socioeconomic subgroups. As a result, no information was obtained regarding how the intersection of race/ethnicity and socioeconomic status relates to family-centered care. While Caucasian families reported higher family-centered care compared to African American and Hispanic families overall, it is unknown if poor Caucasian families perceived services from this same perspective. In addition, although child health status was used as a predictor variable in all analyses, it did not fully capture the severity of the child’s disability. A variable that more comprehensively identified the severity of children’s disabilities would have provided important information about their level of impairment and needed supports, which may have had an even stronger relationship with family-centered care than child health status.

A final limitation of the study relates to the generalizability of results to racial and ethnic minority families. The results of this study only addressed the outcomes of African American and Hispanic families, no other racial or ethnic minorities, and did not account for the wide range of variability in culture, experience, and background of families within each of these groups. In

addition, this study did not take into account how different cultural factors influence interpretation of family-centered principles, interpretation of response options to survey questions, perceptions of children's behavior and development, and perceptions of quality of services received. It is important to exercise caution when interpreting the results of this study with regard to race and ethnicity, and to recognize that there is still much work to be done to better understand the experiences of culturally and ethnically diverse families in early intervention, and what factors contribute to improved outcomes.

This study represents an important contribution to the literature in a number of ways. It adds to the small pool of literature examining the relationship between family-centered care and race/ethnicity, and it was the first known study to specifically examine the relationship between family-centered care and race/ethnicity in early intervention using a nationally representative sample. It also extended the current literature by examining family-centered care as a predictor of early intervention outcomes, which is particularly important due to concerning patterns in the existing literature showing racial/ethnic minority families experiencing less positive early intervention outcomes compared to Caucasian families. The early intervention outcomes targeted in this study addressed both the family and the child, which is well aligned with the goals of early intervention services. In addition, the early intervention outcomes targeted in this study were both subjective and objective. While reported difficulty figuring out what to do about children's behavior and perceived impact of early intervention services on the family were subjective outcomes, the child's special education status in kindergarten was an objective outcome. This study also addressed outcomes immediately following the termination of early

intervention services, and an outcome during a later data collection period, in the child's kindergarten year.

The results of this study are intended to inspire and inform future research to further examine factors related to the enhancement of positive outcomes for ethnically and racially diverse families in early intervention, and beyond. There is a clear need to better determine the root of differences in experiences of family-centered care. It is also important to better understand how cultural differences influence interpretations and experiences of family-centered principles. It may be that family-centered care is a western ideal that is not universally valued or expected. It is likely that there are other conceptual ideas, different from family-centered care, which better encompass the needs and desires of families from different cultures.

Cultural competency in early intervention is another critical area of needed research, specifically with regard to the preparation and training of early intervention service providers. It is possible that a shift in thinking about cultural competency training is needed, from a technical skill acquisition approach to a more interpersonal, relational approach, as described by Roysircar and Lee-Barber (2015). It will be interesting to see how studies, such as the work by Roysircar and Lee-Barber, may better inform the preparation of skilled and effective early intervention providers in the future.

A final area of needed research is the further development of a valid and reliable instrument to assess family-centered care in early intervention, as well as an updated early intervention nationally representative dataset. The family outcomes from NEILS are overwhelmingly positive and encouraging, which underscores the clear success of early intervention programming, and the tremendous amount of research that went into its

development. This study highlighted early intervention service delivery and outcomes with regard to racially and ethnically diverse families as areas of needed continued improvement. An updated early intervention nationally representative dataset would allow researchers to assess if the pattern identified in this study still applies today, and to continue to monitor the success of early intervention since NEILS data collection ended. This database would also provide opportunities for continued research to inform evidence-based practices that will make early intervention a positive and effective program for families of diverse backgrounds for years to come.

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