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Parent Perceptions of Occupational Therapy in Early Childhood Special Education Programs Following Transition from Early Intervention Programs

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PARENT PERCEPTIONS OF OCCUPATIONAL THERAPY IN EARLY CHILDHOOD SPECIAL EDUCATION PROGRAMS FOLLOWING TRANSITION FROM EARLY INTERVENTION PROGRAMS

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University.

by

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ABSTRACT

PARENT PERCEPTIONS OF OCCUPATIONAL THERAPY IN EARLY CHILDHOOD SPECIAL EDUCATION PROGRAMS FOLLOWING TRANSITION FROM EARLY INTERVENTION

By Anita M. Wyrick, M.S.

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science at Virginia Commonwealth University.

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A qualitative approach was used to explore the perspectives of seven parents of preschool age children with disabilities in Virginia regarding occupational therapy and the transition from early intervention (EI) to early childhood special education (ECSE). Open-ended interviews were used to collect data from each family participant and were presented as individual case reports. A cross-case analysis revealed six common categories and four overarching themes. Results indicated that the transition was viewed positively when parents saw benefits of the change and when they were oriented toward the future. Parents viewed the EI and ECSE systems as not sharing their same perspective on the transition. The role of the occupational therapist was viewed as dynamic and shifting in response to the needs of the child, the family and the system. Lastly, communication, involvement and relationships were intimately related. Implications for the field of occupational therapy were given.

CHAPTER I

INTRODUCTION

The Individuals with Disabilities Education Act (IDEA, 1997) has made available specific services to infants and toddlers with disabilities, as well as their families, in an effort to strengthen the role of the family in the education of young children with disabilities. Part C of IDEA focuses on the birth-to-three age group. Part B, Assistance for Education of All Children with Disabilities, addresses the educational needs of children with disabilities ages 3 to 21 years. Within Part B of IDEA, services are provided to address the early childhood special education services for children with disabilities ages 3-5 years.

An important distinction between Part C and Part B of IDEA is that of the role of the family. Part C provides that each child identified as having a disability, and the child's family, should receive a multidisciplinary assessment, a family-directed assessment of resources, priorities, and concerns of the family, and the identification of support and services necessary to enhance the family's capacity to meet the developmental needs of the child (IDEA, 1997). Further, a statement of specific early intervention services necessary to meet the needs of the child with a disability as well as the family is specified in a written document referred to as the Individualized Family Services Plan (IFSP). These services, typically referred to as early intervention (EI), are based on the philosophy of family-centered care. The principle of family centered care, although not specific to early intervention practices, considers that supporting the family is a critical component of any early intervention program and the goal of family support requires services to be organized in such a way that helps families achieve their own goals for their family and child, as well as enabling families to serve as advocates for themselves (Bailey, McWilliam, Buysse & Wesley, 1998).

In addition to the family provision, Part C also provides for occupational therapy (OT) services provided by qualified personnel. Because of the family-centered nature of this law, and the requirement that services be provided in natural environments, occupational therapy services are typically provided in the child's home, and services are provided to both the child (e.g., hands on therapy), and the parent or caregiver (e.g., resources, guidance, emotional support) (Blasco, 2001).

Following the third birthday for a child with disabilities, a transition to Part B, early childhood special education (ECSE) services is mandated by IDEA (1997). In Virginia, these services are typically provided in elementary schools. Further, the provision of a seamless transition from EI services (i.e., Part C), to ECSE (i.e., Part B) is also mandated by IDEA. As such, the law provides for an interagency agreement between both the sending and receiving programs to provide for a smooth transition for families and their children (Blasco, 2001). Best practice in occupational therapy ensures that therapists serving children and their families through this process take the responsibility to collaborate with each other to provide a smooth transition by ensuring that families understand the meaning and importance of transition and the changes that may come as a result (Dunn, 2000).

Early childhood special education is child-centered; that is, services are provided in the interest of the child and outlined in an Individualized Education Plan (IEP). The IEP outlines such services as specialized instruction and related services, including occupational therapy services, to allow the child to benefit from educational services, advance toward attaining annual goals, and to be involved in the general curriculum (IDEA, 1997). In Virginia, parents of children with disabilities are given the option of starting these services at age 2, rather than the national trend of age 3 (Regulations Governing Special Education Programs for Children with Disabilities in Virginia, 2002). Also in Virginia, children are typically served in an early childhood special education classroom, via services outlined in the child's IEP. These services typically occur in a preschool classroom or perhaps in a therapy room at school. Service providers in this case may include an early childhood special education teacher, and other supportive personnel such as occupational therapists, physical therapists, and speech-language pathologists. In Virginia, these preschool classes are usually ECSE classes in an elementary school. Nationally, preschool classrooms may be in Head Start programs or nursery schools.

Occupational therapists have the opportunity to serve children and their families in the early intervention program, as well as the early childhood special education program. As such, occupational therapists can form very close and meaningful relationships with children and families. Particularly in early intervention, parents have come to highly value their child's therapists and the contributions they make to the overall well being of the child and family (Filer & Mahoney, 1996; Minke & Scott, 1995; Wehman & Gilkerson, 1999).

It is this shift in services from family-centered early intervention to child-centered early childhood special education that appears from the literature to be stressful for families, and as such, important to understand from the perspective of the parent. Additionally, this shift in services changes the nature of occupational therapy services from a direct service provision in the case of EI to a related service provision in the case of ECSE and can be a source of additional confusion and stress for families. Many researchers have attempted this examination of parent perceptions (Filer & Mahoney, 1996; Minke & Scott, 1995; Wehman & Gilkerson, 1999) and found overall parent satisfaction with early intervention services. However, parents do not report this same level of satisfaction with ECSE services, or the transition process from EI to ECSE (Hamblin-Wilson & Thurman, 1990). Parents report feeling that they receive more support from the early intervention team than from the public schools (Hamblin-Wilson & Thurman).

This conclusion is troubling and is important to the profession of occupational therapy as service providers in both service delivery models of early intervention and early childhood special education. Although extensive research has been conducted relating to parent perceptions of EI services, limited studies have been conducted regarding parent perceptions of ECSE services. Further, no studies have examined parent perspectives of occupational therapy services specifically in either service delivery model, nor in the transition process. Research regarding parent perceptions of occupational therapy services in an ECSE program following transition from an EI program would be beneficial to the profession of occupational therapy as well as to recipients of these services for several reasons. First, research in this area would help to define the role of occupational therapy and the importance of these services in both the early intervention and early childhood special education settings. Further, research in this area would help define the role of the occupational therapist in the transition process, as well as provide suggestions to therapists to assist parents in the transition from EI to ECSE in addition to being instrumental in program development. Research in this area may better prepare therapists to incorporate family-centered services and best practice as part of an ECSE service delivery, specifically encouraging parent involvement, collaboration, and open lines of communication to make occupational therapy in this setting a rewarding experience for all involved.

CHAPTER II

LITERATURE REVIEW

Legislation

Laws in Special Education for Children with Disabilities

The passage of the Education for All Handicapped Children Act of 1975 (PL 94-142) was enacted by the federal government in support of children with disabilities. This law mandated a free and appropriate public education (FAPE) for all school-aged children. In 1986, following input by families and service providers, P.L. 94-142 was amended by Public Law 99-457. The passage of PL 99-457 required FAPE services for children ages 3 to 5 years. In addition, the law provided incentives for states to include comprehensive and coordinated services for children from birth to age 3. Following reauthorization in 1990, the Education of All Handicapped Children Act Amendment was renamed the Individuals with Disabilities Education Act (IDEA). More importantly, the amendment of IDEA in 1991 made available specific services to infants, toddlers, and their families, and in the process, the role of the family in the education of young children was also strengthened (Blasco, 2001).

Following reauthorization by Congress in 1997, IDEA is currently comprised of four parts: Part A, General Provisions; Part B, Assistance for Education of All Children with Disabilities; Part C, Infants and Toddlers with Disabilities, and Part D, National Activities to Improve Education of Children with Disabilities (IDEA, 1997). The relevance of IDEA to this review will be limited to Part C, Infants and Toddlers with Disabilities, as well as Part B, Assistance for Education of All Children with Disabilities.

IDEA Part C: Infants and Toddlers with Disabilities

The family-centered individualized family services plan. IDEA Part C provides states with financial assistance to develop and implement comprehensive, coordinated, multidisciplinary interagency systems that provide early intervention services for infants and toddlers with disabilities and their families (IDEA, 1997). As defined, infants and toddlers with a disability means a child under 3 years of age who needs early intervention services because of developmental delays in one or more developmental areas (including motor and social/emotional areas), or who has a diagnosed physical or mental condition which has a high probability of resulting in developmental delay (IDEA).

Further, IDEA (1997) provides that each child identified as having a disability, and the child's family should receive: (1) a multidisciplinary assessment, (2) a family-directed assessment of the resources, priorities, and concerns of the family, and the identification of the supports and services necessary to enhance the family's capacity to meet the developmental needs of the child; and (3) a written individualized family services plan (IFSP). In addition, (4) the provision of a service coordinator and (5) steps to be taken to support the transition of the toddler with a disability to preschool or other appropriate services is provided. The IFSP contains among other things, a statement of specific early intervention services necessary to meet the unique needs of the infant or toddler and the family, including the frequency, intensity, and method of delivering services. (IDEA).

The hallmark of this provision and the IFSP is that it is family-centered (Blasco, 2001). Various labels have been used to describe this family support movement including parent empowerment, family-focused, and family-centered care (Bailey, Buysse, Edmondson, & Smith, 1992; Rosenkoetter, Hains, & Fowler, 1994). The term family-centered care however, has been well established in the literature (Crais & Belardi, 1999; Filer & Mahoney, 1996; Wehman & Gilkerson, 1999) and will be used throughout this document. These comprehensive services are commonly referred to as Early Intervention and are often provided as a home-based service. In Virginia, the Early Intervention program is called the Infant and Toddler Connection of Virginia.

Family–centered care in IDEA Part C. The passage of Public Law 99-457 in 1986 and the subsequent reauthorizations has considerably strengthened the role of the family in the education of young children (Blasco, 2001). As such, the family-centered philosophy was incorporated into programs that serve very young children with disabilities. In addition, the requirement that professionals who serve children with disabilities from birth to age 3 collaborate with the child's family to create an IFSP that assures services for both child and family was provided. This plan should include family concerns, resources, and priorities provided consistently with family preferences, so that the family can increase its capacity to meet the child's special needs (Turnbull & Turnbull, 1997).

Extensive literature on family-centered practice has yielded four major characteristics that define practices as family-centered. These characteristics are:

inclusion of families in the decision making, planning, assessment and service delivery process; development of services for the family as well as the child; goal development and prioritization by the family, and respect for families' choices regarding the level of their participation (Bailey et al., 1992; Murphy, Lee, Turnbull, & Turbinville, 1995; Turnbull & Turnbull, 1997). The family-centered philosophy considers that supporting the family is a critical component of any early intervention program. The goal of family support requires services to be organized in such a way that helps families achieve their own goals for their child and family as a unit, as well as enabling families to serve as advocates for themselves (Bailey et al., 1998).

McBride, Brotherson, Joanning, Whiddon, and Demmitt (1993) conducted a qualitative study using descriptive interviews to investigate the meaning of family-centered practice and the extent to which it was being implemented. The perceptions of both parents and professionals who participated in the development of IFSP's were examined. Fifteen families of children with developmental delay receiving an IFSP were interviewed. The mean age of the child with an IFSP was 16.2 months. Fourteen professionals were interviewed as well, including early childhood special educators, one social worker and one occupational therapist. Semi-structured interviews of approximately 1-½ hours in length yielded three sets of themes related to the perceptions of the focus of services on the family. The first set of themes identified were attention to family concerns beyond the specific needs of the child, respect for family values and routines, and involvement of fathers, siblings, and other family members. The second set of themes, which related to family roles and choices in decision-making, were described as parent roles in decision-making, choices for decision-making, and attitudes and feelings about decision-making. The third set of themes to emerge related to the strengthening of family function through intervention. Here themes such as increase in confidence and parenting skills, emotional well-being of family members were improved, and child's progress enhances family functioning were found. The author concluded that families expressed overall satisfaction with services, however some professionals or programs were clearly more family-centered than others (McBride et al., 1993).

Occupational therapy in family-centered care. Professionals who value, encourage and commit themselves to meaningful involvement with families in planning and implementing services are practicing family-centered care, and are thereby creating a successful communication strategy for intervention (Salisbury & Dunst, 1997). In addition to the family provision, Part C of IDEA also provides for occupational therapy (OT) services, and that services be provided by qualified personnel. Under Part C, occupational therapy may be provided as a direct service in the case of the IFSP, meaning occupational therapy may be the only service an infant or toddler receives. Occupational therapy, like all other EI services, should also be provided in natural environments and community settings in which children without disabilities participate (IDEA, 1997). Thus, services can be provided in a child's home, daycare center, preschool, or other natural environment. In the field of occupational therapy "professionals have the responsibility to provide family-centered care (i.e., to honor the family's priorities and style in designing and implementing intervention plans)" (Dunn, 2000, p. 4). This is considered best practice for the profession of occupational therapy.

The role of occupational therapy is considered in the context of family-centered care. Using their unique perspectives, occupational therapists are able to create links that provide the infrastructure for the supports of other disciplines to meet the needs of the families and priorities for performance (Dunn, 2000). Family-centered care in OT is supported by The Standards of Practice for Occupational Therapy (American Occupational Therapy Association [AOTA], 1998). This document provides standards for the occupational therapy practitioner for the delivery of occupational therapy services that are client centered and interactive in nature (AOTA). Throughout this document the family is referred to as family members, significant others, and appropriate others. As such, occupational therapists must consider the needs of the family in such aspects of care as evaluation, intervention planning, intervention, and transition.

IDEA Part B: Assistance for Education of All Children with Disabilities

The child-centered individualized education plan. In addition to Part C, IDEA also provides for a free and appropriate public education for all children with disabilities between the ages of 3 and 21, inclusive. While Part C is family-centered, Part B of IDEA is child-centered; that is, services are provided in the interest of the child and outlined in an Individualized Education Plan (IEP) (Rosenkoetter et al., 1994). Terms used to describe this child-oriented focus include child-based, child-centered, and child-focused (Bailey et al., 1992; Rosenkoetter et al., 1994; Wehman & Gilkerson, 1999). For consistency, the term child-centered will be used throughout this document.

The IEP includes such services as specialized instruction, and also a statement of the special education and related services, including occupational therapy services, to allow the child to advance toward attaining annual goals, to be involved in the general curriculum, and to be educated and participate with non-disabled peers (IDEA, 1997). The distinction that must be made clear here is the provision of child-centered services as guided by the IEP. For children ages 3 to 5, all services specified in the IEP are often referred to as Early Childhood Special Education (ECSE) and are commonly provided in a preschool (center-based) context. In Virginia, ECSE classes are typically housed in elementary schools, and parents are given the option for ECSE services to begin at age 2 (rather than age 3).

Occupational therapy in child-centered services. Occupational therapy is provided as a related service under Part B of IDEA, meaning OT services must supplement other services the child may receive in special education. Occupational therapy in a school-system, by virtue of a child's individualized education plan, is child centered. However, models of service provision (i.e., service delivery) must also be included in this discussion. Service delivery models are ways that occupational therapists use their time in the intervention process (Dunn, 2000). Service delivery models allow a continuum of services to be responsive to the needs of children and their families. Service delivery models include direct services that are carried out with a child individually or in a small group, and integrated therapy that supports a child's performance within his or her natural environment by providing training by the occupational therapist of another person in the child's environment who carries out the plan and monitors the child's progress. In addition, consultation is a service delivery model where the therapist consults with an individual (often the child's teacher) who is responsible for the outcome. In this model the therapist collaborates with the adult who is carrying out the therapy program (Dunn).

Transition From Early Intervention to Early Childhood Special Education

Laws in the Transition

Shift in Emphasis From Family-Centered to Child-Centered Services

IDEA provides for a smooth transition for families and their children by the child's third birthday by providing for an interagency agreement between both the sending and receiving programs (typically the early intervention program to the early childhood special education program) (Blasco, 2001). It is this shift in focus of services from the family-centered services of Part C to the child-centered services of Part B that is referred to as transition (Blasco). Well-planned transitions can be both satisfying and enabling for children and their families, however this process can also be a source of stress and present challenges to parents and children (Rosenkoetter et al., 1994).

For occupational therapists, best practice ensures that therapists contribute in both the sending and receiving program during the transition period. Dunn (2000) describes best practice as decisions and actions by a professional based on evidence and knowledge that are reflective of the most current and innovative ideas available. Best practice in occupational therapy is demonstrated by the therapist in the sending program (i.e., early intervention) by ensuring progress is clearly documented as well as ensuring that current levels of performance and interventions that have been successful (or unsuccessful) are also documented. For the therapist serving in the receiving program (i.e., early childhood special education), the responsibility is to thoroughly review all documentation about the child in preparation for educational planning. Further, therapists serving or receiving children through the transition process have a responsibility to collaborate with each other to ensure a smooth transition for the child and family. Both therapists can make sure that families understand the meaning and importance of transition, and the changes in the provision of services that may come as a result of the transition (Dunn).

Perceptions of Parents and Professionals

Perceptions of Intervention Services

Parents' Perceptions of Intervention Services

Parent perceptions of services are important to any early intervention program. In considering aspects of parent perception of services, researchers have examined both home-based services for children in early intervention (i.e., ages birth to three) and center-based services in early childhood special education (i.e., ages 3 to 5). However, this distinction in service delivery is not always clear in the literature. An attempt will be made to make this distinction more clear as the research is further examined.

Mahoney, O'Sullivan, and Dennebaum (1990) conducted a national survey of mothers' perceptions of family-centered early intervention using the Family Focused Intervention Scale. Five hundred and twenty-seven mothers of children from birth to 6-years-old with disabilities were surveyed. Here a distinction is made between mothers having children ages 0 to 3, who are receiving services via an IFSP, and mothers having children ages 3 to 6, who are receiving services via an IEP. The results of this study indicated that intervention services of younger children (ages 0 to 3 years) had a significantly greater family focus than did services for children ages 3 to 6. The greatest difference between the two age groups was family instructional activities such as showing the parent how to play with the child and providing a weekly instructional plan. Interestingly, the percentage of mothers' indicating that they wanted family instructional activities declined between age groups, with 71% of mothers of children ages 0 to 3 wanting these services and only 57% of mothers of children ages 3 to 6 desiring family instructional services. This study design failed to discriminate between mothers whose children received early intervention services and those who received services in center-based programs so that it is not possible to draw conclusions about whether the mothers' whose children received center-based services felt that the service providers in these programs should provide some type of family centered component (Mahoney et al.).

In an effort to gain descriptive data on families' perceptions of early intervention services, McWilliam et al. (1995) utilized a mixed method design of both qualitative (i.e., semi-structured interviews of 6 families) and quantitative (i.e., a 30-item questionnaire) methods to gather data on 539 parent of infants, toddlers and preschoolers receiving early intervention services. Results of this study regarding family perceptions of professionals' focus indicate that family perceptions differed according to the age of the child. Families of children under 3 years of age were generally more satisfied than families of children over 3 years of age. These findings are important because at age 3, children typically enter a center-based program and services are then guided by a child-centered IEP rather than an IFSP. Also in this study, families reported overwhelmingly high satisfaction with early intervention programs, and in-depth interviews revealed that the source of much satisfaction was the personal support provided by individual professionals, as indicated by the response from one parent “It was like they were professional as far as working with my child but they also were caring too” (McWilliam et al., 1995, p. 55).

The perceptions and satisfaction of parents of children receiving special education services were explored by Plunge and Kratochwill (1995). In this quantitative study of a mid-western metropolitan school district, 112 parents of children receiving special education services grades preschool through fourth grade were administered a three-page questionnaire. A portion of this survey asked parents to rate their satisfaction of such areas as the child’s IEP, school personnel, special education services, and social integration using a 5-point scale. The survey also posed questions regarding the parents’ level of involvement in special education activities. In findings similar to the findings of McWilliam, et al. (1995) parents indicated the greatest level of satisfaction with school personnel. The lowest level of satisfaction was with the child’s level of social integration. Areas of greatest involvement for parents include parent comments during the IEP meeting regarding their child’s strengths and weaknesses (93.3%) as well as signing the IEP. Areas of low parental involvement include evaluation of special education services (19%) and attending advocacy groups and parent workshops (21.6%). Correlations between parent participation and parent satisfaction were not significant. This study is important because it expounds on the importance of family-professional relationships with children receiving special education services through the school system (Plunge & Kratochwill).

Filer and Mahoney, in a 1996 study, investigated perceptions of service providers and parents in relationship to the level of services families receive and the value of these services. Participants in this survey of 73 early intervention services providers and 193 parents of representative families receiving early intervention services in five states were included. Responses indicated that discrepancies between families and providers in their perceptions of what services families value as essential and what families are actually receiving were substantial. Both parents and professionals viewed early intervention services as focusing more on child-centered as opposed to family-centered services. In this study, parents indicated receiving substantially lower level of services than professionals report delivering in the area of child information, system engagement, and resource assistance. The authors concluded that this lack of correlation between the views of families and professionals may be due to difficulty for some professionals in describing what services are actually family services, or perhaps providers and families are limited in conversation about the services actually taking place. Additionally, it is proposed by the authors that this lack of correlation may be due to an unsystematic approach to working with families. Similarities between what parents and professionals reported were found in the areas of level of instructional activities and personal/family assistance.

The impact of two components of family-centered services on children and their parents were examined by Mahoney and Bella (1998). Utilizing a sample of 47 families who attended 1 of 36 early intervention programs, the authors examined the comprehensiveness of family services as well as the responsiveness of intervention services to family needs over a 12-month period. Findings from this study indicated that approximately forty-five percent of families reported receiving a comprehensive array of family services including extremely high levels of services related to their child’s development (e.g., child information, educational activities) and moderate levels of services such as personal family services and resource assistance (e.g., family level concerns). Nearly fifty-percent of families reported that the scope and intensity of the services that they received equated with their own views of what they believed was needed. In contrast, a substantial portion of the sample also appeared to be receiving low levels of family-centered services and also indicated considerable discrepancies between the types of services they received and the types of services they believed was needed. This study exemplified the considerable variability to which early intervention programs emphasized family-centered components (Mahoney & Bella).

Parent perceptions of the benefits of early intervention services are similar. In an Illinois study on parent perception of early intervention services, Wehman and Gilkerson (1999) conducted a qualitative investigation and examined written responses to three open-ended questions submitted by 248 consumers of early intervention services in Northern Illinois. Seven hundred and forty-two families were surveyed in this study, indicating a return rate of 33%. This report concluded that parents highly value their early intervention programs and services. Most valued services were reported to be technical knowledge/skill and emotional support of service providers and direct child-focused therapy services. Forty percent of the parents in this study reported that they valued the technical knowledge/skill and emotional support of service providers and 34% felt that receiving therapy for their child was the most beneficial aspect about early intervention. Parents highly valued the information and knowledge that their therapists and educators had about disabilities and child development.

In an attempt to explore how special educators can be more responsive to families' needs, Pruitt, Wandry, and Hollums (1998) utilized qualitative methods to examine parents' response to questions regarding educator sensitivity to family needs and how educators can be more responsive to these needs. Of the 78 families of children or young adults with a disability interviewed in this study, only 7 indicated overall satisfaction with the educators with whom they interacted and the special education system. Parents indicated wanting educators to listen to them, respect their contributions, and listen to their personal issues. In addition, 23% of parents responded that quality and quantity of communication between parents and professionals should be improved. Parents in this study reported a desire to be listened to, to establish effective communication with professionals, to receive education about various disabilities, to have professionals demonstrate sensitivity and respect for their children, and to improve the IEP process. The authors suggest that special education providers may foster unsatisfactory levels of communication and collaboration and that by facilitating more sensitive and productive communication and decision-making, the parent/professional partnership can be strengthened (Pruitt et al.).

Although these studies are not specific to occupational therapy, they do reveal that overall perceptions of parents of children receiving special services consider communication with service personnel a necessity in establishing a positive relationship. As such, communication is described as transmission of various kinds of messages, including information related to needs, perceptions, desires, knowledge, or feelings (Goldstein, Kaczmarek & Hepting, 1996). Communication can involve written, verbal and non-verbal forms. When communicating with parents in an early intervention or early childhood special education context, communication is often verbal such as meetings, conferences, one-on-one discussions, and telephone conversations. In addition, communication can include written strategies in the form of assessments, objectives, progress notes, or informal notes from a teacher or therapist and is the means by which an empowering context can be created (Turnbull & Turnbull, 1997).

In addition to the importance of communication to families, these studies also exemplify the perceptions of parents that technical knowledge and emotional support of service providers are important. The profession of occupational therapy can derive important information from these studies in the pursuit of best practice as well as by examining the perceptions of other professionals working with this population.

Parent and Professional's Perception of Assessment and Involvement

Bailey, Buysse, Edmondson, and Smith (1992) examined the perceptions of professionals pertaining to family-centered care. In this study, rating scales are utilized to assess four dimensions of family involvement. Participants in this study consisted of 180 professionals working in early intervention in four states. In an effort to determine the status of family-centered early intervention programs and the perceptions of professionals (e.g., teachers, therapists, psychologists, social workers) regarding current and ideal practices in working with families, Bailey et al. found that professionals perceive a substantial discrepancy between how they currently involve families in early intervention programs and how families ideally should be involved, particularly in considering the level of parent involvement regarding decision-making in assessment, parent participation in the assessment process, team meetings and decision making, as well as the provision of family goals and services. Professionals in this study also identified barriers to an ideal early intervention program. Responses indicated that family barriers and system barriers were perceived as the most substantial reasons for the discrepancies between parent and professional perceptions. Professionals in this study suggested that many families may not have the knowledge or skills to participate fully in early intervention planning and decision-making, or may not be interested in these roles. This study exemplified the need for closer relationships between families and service providers, and concluded that professionals must consider the needs of the family in addition to the needs of the child if services are to be provided in the spirit of IDEA. Identified difficulties in family barriers may indicate a need for additional parent training or support to participate at the level they choose. Additionally, system barriers, such as state or administrative policies, lack of available staff, and established patterns of service provision that were inflexible, were identified as interfering with offering an ideal EI program (Bailey et al.).

In an effort to describe and facilitate parent involvement in one early childhood special education program in a large Midwestern urban school district, Shriver and Kramer (1993) distributed surveys to parents of children ages birth to 6 receiving early childhood special education in either a home-based or center-based program. Of the 426 surveys distributed, a total of 181 surveys were returned. Survey items centered on the initial evaluation, multi-disciplinary team process, and IEP components of the program for which the children were involved. Thirty-two percent of the 181 respondents were parents of children receiving home-based services and 68% were parents of children served in the center-based program. Forty-one percent of respondents' children were served under the label of Speech/Language Impaired. In the area of initial evaluation, respondents reported general satisfaction with their involvement and input into the evaluation to determine eligibility. The majority of parents indicated that they did wish to attend the multi-disciplinary team meeting (81%), and desired some involvement in this process. The majority of respondents reported satisfaction with their involvement and input into their child's IEP, although no frequency was reported. When examining the parent-teacher contact in this study, the majority of parents in the center-based programs indicated satisfaction (81%) with the amount of contact with the teacher. Contact is generally reported in the form of parent visitation, telephone, or communication notebook. Nineteen percent of the parents of children in the center-based program indicated a desire for more frequent contact with the teacher. Because this survey consisted of only one early childhood special education program, and because the response rate was so low, generalizations to the larger population cannot be assumed. However, this study does give us some indication of how parents of children receiving early childhood special education services might perceive their level of involvement and communication with their child's service providers (Shriver & Kramer).

Minke and Scott (1995) further explored the concept of parent participation and perceptions in a qualitative study investigating parent-professional relationships in early intervention. Employing naturalistic methods, nine families, ten direct service providers, and four administrators were interviewed and videotaped during IFSP meetings. Two major themes which emerged were those of the role of parent-staff personal relationships in encouraging active parent participation, and staff reactions to parent participation. Parent-staff bonding was cited as one of the major elements that appeared to make the process work. Benefits from this close relationship were cited as including emotional support received by the parent, staff members noting easier joint problem solving, greater acceptance of program limitations, and parents' increased willingness to try new behaviors. This study contributed to the evidence that parental-professional relationships influence the level of parent participation.

Crais and Belardi (1999) examined the perceptions of families in the area of family participation in child assessment. In this study, a self-rating instrument was distributed to families and professionals in North Carolina following assessment of children from birth to 3 years old suspected of having developmental delays. Instruments were distributed in sets of three, two instruments targeted for professionals involved in the assessment, and one targeted to the family of the child assessed. Of the 246 instruments distributed, 81 responses were obtained (58 from professionals and 23 from families). Findings indicated that parents perceive the practice of professionals spending time to find out the family's most important concerns very high (97.5%). Parents reported that assessment procedures allowed them the option to describe their child's daily routine (95.5%), to be present for all assessment activities, (90.9%), and to spend time identifying the next steps in the planning process (90.9%). In these areas, family and professional congruence was reported in all aspects of both actual and ideal practices, with the exception of time spent identifying next steps in the planning process. Professionals rated the area of time spent identifying next steps in the planning process in both actual and ideal practices much lower than that of the parents. Due to the relatively low response rate in this study, caution should be utilized in making generalizations, however this incongruence in professional and family perceptions of ideal and actual service delivery is important in that it informs professionals, such as occupational therapists, that although they may think they are in tune with what parents want and need, that they may not have an accurate picture of parental perceptions. This study provides professionals with specific areas to check their current and best practice in assessment of young children.

The concept of parent and professional cooperation is conceptualized by Thompson (1998). Because this study was conducted in Australia, generalization to the U.S. population should be made with caution. In this study, a qualitative, ethnographic approach using semi-structured, in-depth interviews and demographic questionnaires was used to study ten mothers of children ages 0-6 with disabilities and high support needs as well as receiving occupational therapy services. The aim of this study was to identify and explore parents' perceptions of occupational therapy services and the impact of these services on daily life. It was clear from this study that did specifically examine occupational therapy services in early intervention that "mothers thought in terms of early intervention services in general, rather than in terms of occupational therapy specifically" (Thompson, 1998, p. 206). This study indicated that mothers perceived relaxed and friendly services providers as having a greater insight into family life, and therefore a greater capacity to provide services to meet family needs. Thompson concluded that mothers in this study perceived that the personal support provided to them by therapists was as important as hands-on intervention with the child.

Peterander (2000) further taps into the idea of parent-expert cooperation. Because this study was conducted in Bavaria, generalization to the U.S. population should also be made with caution, as the Bavarian early intervention system may be quite different than that in the U.S. In this survey of 984 mothers of children receiving early intervention services, a 26-page survey was distributed and results indicated that mothers who work closely with professionals experienced professional cooperation as equally important for themselves as for their child and as contributing to treatment success.

Of the many studies that have been conducted to examine the perceptions of parents whose children received specialized services, no studies specifically examined the parent's perceptions of children receiving solely early childhood special education services (ages 3-5 years). Interestingly, many researchers did distinguish between these groups when conducting research, however little emphasis has been placed on the very different service delivery models used in early intervention and early childhood special education (i.e., IFSP, family-centered and IEP, child-centered) when examining parent perceptions. Further, no studies addressed parent perceptions of occupational therapy services specifically, or parent perceptions of therapy services in general with this population.

Parental Perceptions of the Transition

Parental satisfaction with transition. Although several studies have examined the services and parent perceptions of early childhood programs, none have closely examined the very important transition between early intervention services (i.e., IFSP driven services) and early childhood special education services (i.e., IEP driven services). A primary goal for service providers is a successful transition to an appropriate setting for the preschooler, ensuring that all of his needs are met in a natural and least restrictive environment. As such, it is important to examine this shift in services from the perspective of the parent.

In an early study published in 1990, Hamblin-Wilson and Thurman examined the transition from early intervention to a mixed-categorical kindergarten. Three hundred-seventy-nine parents of children who transferred from an early intervention program in Philadelphia were mailed a questionnaire pertaining to parent's perceptions of the transition process. Of the 379 questionnaires mailed, ninety-one useable questionnaires were returned. Four factors of transition were explored in this study: satisfaction, importance of service relationships, explanation and support, and importance of preparation. The results relevant to this discussion indicate that 60.4% of the total respondents felt that they received more support from the early intervention program than from the public schools. Although the response rate in this study was extremely low, findings from the returned questionnaires suggest that schools, and transition teams within schools, might need to do a better job in supporting and communicating with parents during this time. Indications from this study are that initially, transition teams were not doing an optimal job in supporting and communicating with parents (Hamblin-Wilson & Thurman).

Hanson et al. (2000) conducted a study to gain a better understanding of family and professional experiences in the transition process for children with disabilities at age 3. The researchers conducted the study through four national research sites, representing a variety of geographical locations. Further, family participants were evenly distributed among geographical sites. A total of twenty-two family participants were recruited and data was collected through structured interviews, participant observation in transition meetings, and document analysis. Interviews were conducted with primary caregivers, service providers, and with school system representatives, as well as others involved in the transition process (Hanson et al.).

By examining the choices and decisions of families and professionals during the transition process Hanson et al. (2000) specifically examined the nature of the transition process, information and options presented to families, and preferences and choices related to inclusive preschool services. Six themes emerged from this study. The first was that transition is an event not a process; parents and professionals alike saw the transition as a specific event or meeting rather than an extensive process of planning for the child and family. The transition was viewed as a formality that would include major decisions about placement options and the nature of services. The second theme was described as impact of shifting systems on families and children; here anxiety by parents was expressed concerning moving from one system to another and was often described with a sense of dread. The third theme identified in this study was that of importance of information exchange and communication; most parents expressed a strong desire to be heard and to participate in the transition process. Parents expressed a crucial need for information exchange prior to the transition. Limited family choices was identified as the fourth theme to emerge; families expressed their limited options for the type or location of their child's preschool services. The availability of service options were specific to the school district and appeared to play a major role in the range of options provided to parents. The fifth theme identified in this study was that of child characteristics and readiness; professionals and parents alike identified child behavior and developmental level as playing a key role in decision-making and discussions, particularly when issues of placement and inclusion were discussed.

Parents and professionals alike expressed concern of the child's readiness to participate in preschool and especially in inclusive preschools. The sixth and final theme identified was described as facilitators in the transition process; several factors that facilitated the transition process for both families and professionals were noted, such as information exchange and pre-transitional informational meetings. Additionally, parents identified the desire to have the opportunity to visit preschool programs and have a key person to help them move through the process, as a major factor influencing the family's role in decision-making and participation (Hanson et al.).

As Rosenkoetter et al. (1994) was cited for saying at the start of this discussion, transition can be both satisfying and enabling for children and their families, and be a source of stress and present challenges to parents and children. The literature is somewhat void of the perceptions of parents during this transition process. As indicated by the research of Hanson et al. (2000), a seamless system of service delivery can be addressed through closer links with families. Occupational therapists have a role in the seamless transition process as indicated in the professions standards. Standards of Practice for Occupational Therapy (AOTA, 1998) require that the occupational therapy practitioner identify needs and prepare a formal transition plan as well as cooperate with the client, family members, significant others, team, and resources available in the community to facilitate the transition process. This is considered best practice in the field of occupational therapy.

Significance of the Research

IDEA provides for family-centered services for very young children with developmental delay; however no such provision exists for preschool age children receiving services in an early childhood special education programs. Despite this lack of provision of family-centered service, best practice in occupational therapy is based on family-centered principles and as such is specified in The Standards of Practice for Occupational Therapy (AOTA, 1998). The literature presents ample evidence indicating that the support of families is a critical component in early intervention. Further, the literature indicates that parents perceive professionals demonstrating respect for the family, attention to family concerns and involving families in the decision making process very important in the success of their program. Additionally, parents indicated that communication, receiving information about their child's disabilities and development and knowledge of how related services will be delivered following transition are important to them. Overall, families of infants and toddlers (birth-to-three) are more satisfied with their early intervention services than families of children ages three-to-five, and parents cite satisfaction with personal support provided by individual professionals as crucial to this success. The literature also suggests that direct child-focused therapy services as provided by occupational therapists are highly valued by parents.

The literature further indicates that parents value supportive professionals and those professionals who address their personal needs as well as the needs of their children throughout all aspects of childhood intervention, including early intervention, early childhood special education, and the transition process. Parent-staff bonding is cited as one of the major elements that make the process of special education work. Additionally, parents indicate that involvement in the assessment process and decision-making was important and described this involvement as ideal.

Several factors for successful transitions are cited in the literature such as communication, caring professionals, and parent involvement however it is unclear to what extent these factors are being utilized in the transition process. Additionally, little literature exists that specifically addresses parent perceptions of the post-transition placement of children in early childhood special education programs. More importantly, there appears to be a gap in the literature with respect to examining parental perceptions of occupational therapy services specifically in the provision of early childhood special education programs. This review of the literature appears to support the family-centered care provisions of IDEA pertaining to services for children receiving early intervention services. In addition, family-centered care is evidenced in the literature by the high satisfaction rates that parents report having in regard to their early intervention services. However, no such family support is evident in the literature concerning the early childhood special education services provided by IDEA.

The benefits to determining parent perceptions of occupational therapy services in an early childhood special education program following transition are many. First, by supporting parents through the transition process and ensuring a smooth and seamless transition, occupational therapy can alleviate the fears and apprehension of parents and families experiencing this event, thus using best practice. Further, by examining parent perceptions of children having already transitioned to a preschool program and receiving occupational therapy services, occupational therapists can gain valuable insights into what services parents would like to see in the early childhood special education. This knowledge could lead to occupational therapists' understanding of how to make the transition process less stressful for families. The literature indicates that important and satisfying aspects of the early intervention programs include frequent communication, family involvement, child-centered services, as well as strong parent-professional relationships. These aspects of an early intervention program that parents deem important and satisfying are also indicative of best practice for occupational therapists.

It is these very aspects of best practice that occupational therapists are concerned with; however there appears to be a gap in the literature specifically addressing the components of parent communication, involvement, and child-centered services that appear to exemplify best practice with the population of children receiving early childhood special education services. There is a need to obtain a deeper understanding of parent perceptions of occupational therapy services throughout the transition from early intervention to early childhood special education, the challenges families face, and the services they perceive as essential in order to meet these challenges. Research that explores parent perceptions of occupational therapy services in early childhood special education would be beneficial in defining the role of occupational therapy in the transition to early childhood special education programs, as well as defining the role of occupational therapy in supporting families and promoting best practice for occupational therapists in early childhood special education.

Purpose Statement

The purpose of this research was to explore parent perceptions of occupational therapy services in early childhood special education programs following transition from early intervention programs, and how these perceptions have changed over time. Parental perceptions were explored through individual interviews using guiding questions that were broad in nature, as qualitative research needs to remain sufficiently open and flexible to permit exploration of the phenomenon under study (Patton, 2002). These questions evolved and changed over the course of this study and were subject to revisions, additions and deletions as the study progressed. The initial guiding questions included the following:

1. How do parents of children who formerly received early intervention services and who currently receive early childhood special education services view the role and benefits of occupational therapy in their child's preschool program?
2. How do parents conceptualize the differences between service delivery of occupational therapy in early intervention and early childhood special education?
3. How do parents describe the type and extent of communication with their child's occupational therapist as school? How has this changed from that of early intervention? How do parents describe the effectiveness and their level of satisfaction with this communication in comparison to the effectiveness and satisfaction with the communication they had with their child's OT in early intervention?
4. How do parents describe the type and extent of their involvement with their child's occupational therapist at school? How has this changed from that of early intervention?

5. In what ways can occupational therapists help make the transition process flow smoothly for parents and children transitioning from early intervention to early childhood special education?

This study investigated parent perceptions of occupational therapy services in early childhood special education programs. Of particular interest was how parents' perceptions changed over the course of early childhood special education in key areas identified in the literature as being especially important to parents of children receiving early intervention services. These key areas included child-centered therapies, communication, and involvement. In this study, interview questions and observations were based on these identified aspects of early intervention as they relate to occupational therapy services in early intervention, the transition, and early childhood special education programs.

CHAPTER III

METHODOLOGY

Methods

Type of Study

Qualitative Methodology

In this study, the researcher utilized qualitative research methods to explore the perceptions of parents in regard to occupational therapy services in early childhood special education programs. Through the use of in-depth, semi-structured interviews and extensive field notes (e.g., journal) the researcher provided a detailed description of the perceptions of seven parents of students with disabilities enrolled in ECSE programs throughout four school districts in the southeastern Virginia area. Perceptions of parents regarding occupational therapy services as these services related to their experience in ECSE, the early intervention services, and through the transition to early childhood special education were elicited. Qualitative research designs are emergent, and as such the methods used in this study were altered as categories became apparent throughout the data collection and analysis process. Alterations to the methodology were recorded in the fieldnotes.

Qualitative research has its roots in anthropology and is a method of research that, by design, is flexible and elastic and involves merging various methodologies. Qualitative methods are holistic and aim for an understanding of the whole and are focused on understanding a social setting or phenomenon without making predictions about that phenomenon (Polit & Hungler, 1995). Decisions about study designs, obtaining data, and scheduling were made as the study unfolded and required that the researcher become intensely involved in the study, acting as the research instrument. To increase awareness of potential bias, the researcher prepared a self-as-instrument statement (Appendix A) (Polit & Hungler). Qualitative research methods seek to explore, describe, understand, or interpret the life experiences from the experience of those living it (DePoy & Gitlin, 1994). The researcher utilized open-ended interview questions using a semi-structured format and an interview guide (Appendix B) to obtain a rich, thick description and understanding of the perceptions of OT among seven parents whose children had received early intervention services and whose children continued to receive services through ECSE.

Sampling Plan

Using purposive sampling methods, the researcher selected a total of nine parents from seven families whose children with disabilities were receiving occupational therapy services in ECSE programs in public schools in southeastern Virginia and who had formally received EI services. Purposive sampling provides information-rich cases that illuminate the research questions (Patton, 2002). Criterion for selection included the following:

1) Parents had children who were identified as having a developmental delay or as having a specific disability.
2) Participants were English speaking.
3) Participants were the mother of the child or both the mother and the father.

4) All participants' children formally received occupational therapy services in an early intervention program in Virginia.
5) All participants' children had an active individualized education plan at the time of the interview.

Attempts were made to select participants who transitioned to the ECSE program within the last two school years because it was felt that their recall of the transition would be most clear. Two of the seven parents met this criteria, however the other five parents were included whose children had received ECSE services for three years. This was due to limited response from parents meeting the two-year criteria. The opportunity to balance the sample in the areas of ethnicity, socioeconomic status, frequency and duration of occupational therapy services, and severity of disability was not possible due to the limited number of potential participants.

Access and Entry

This research proposal was submitted to the Institutional Review Board (IRB) of Virginia Commonwealth University following successful defense of its content and approved on January 10, 2002 following requested revisions. A copy of the IRB letter of approval is provided in Appendix C. Access to participants was supported through the Virginia Department of Education (see Appendix D, letter of support from Virginia Department of Education) and recruited through various parent organizations such as The Parent Resource Center by first sending via first class mail an organization solicitation letter (Appendix E) along with a research description letter (Appendix F) asking for assistance in recruiting participants. Access to participants took one of the following formats: First, a research description letter (Appendix F), was sent to parent organizations asking someone there to first contact potential participants to ask permission to reveal their name and phone number to the researcher. The researcher then made contact with interested potential participants by telephone and provided them with a more detailed description of the study so that they could make an informed decision about their willingness to participate. The alternative format for access included other parent participants provided the researcher with names of other potential participants, following obtaining the potential participants permission to reveal their name and phone number to the researcher. The researcher then contacted by telephone potential participants in the manner described previously. The research description letter (Appendix F) was used in all telephone contacts when describing the study to potential participants. In many instances, a copy of the research description was either sent via traditional mail or electronically to potential participants. Dates, times, and locations for interviews were then scheduled with parent participants. The consent form was either mailed via traditional mail or sent via electronic mail to the participants one week prior to the interview. Informed consent forms were explained by the researcher and signed by the participant prior to interviews being conducted. A copy of the consent form can be found in Appendix G, along with a complete list of open-ended interview questions described earlier.

Settings

Parent participants were interviewed at locations of their choice. Five of the seven interviews were conducted in the family home. The remaining two interviews were conducted at the child's preschool. All efforts were made, however, to choose a location that was private and free of noise and distractions, and this was explained to the participant. This was done to ensure confidentiality and clear audiotaping of the interview.

Role of the Researcher

The primary role of the researcher throughout the data collection and interpretation period was to elicit and document information provided by the participants. In an effort to facilitate a reciprocal relationship with the participant, the researcher attempted to establish rapport and a sense of trust. The researcher was courteous, respectful, and adhered to principles of person-first language when conducting interviews. A verbal and written expression of gratitude was extended to the participants for involvement in the study (Appendix H).

Data Collection

Type of Data

Methods of Data Collection

The aim of this study was to collect rich, thick, descriptive, and detailed information so that complete and accurate descriptions of parental perceptions of occupational therapy services in ECSE and EI programs could be obtained. Data was collected using field notes and semi-structured interviews. The primary agent for data collection was face-to-face interviews using an interview guide developed by the researcher (Appendix B), as this allowed the participants to express their perspectives in their own words for the researcher to capture the complexities of the individuals' experiences and perceptions (Patton, 2002). Further, in-depth, face-to-face interviews allowed the researcher to elaborate on particular topics, clarify meaning of responses, and observe emotion and body language of participants that otherwise would be lost.

In addition to guiding questions, the interview guide also included probes to guide additional questioning if the initial questions were not answered by the participant on the five key topic areas: role and benefit of occupational therapy, service delivery, communication, parental/family involvement, and transition. The general interview guide approach involved outlining general interview questions without any particular order as well as providing wording for questions to prompt the researcher when conducting interviews. This method allowed for a checklist style of interviewing ensuring that all relevant topics were addressed (Patton). In addition, the interview guide also contained an initial screening section to verify that participants continued to meet the criteria for inclusion.

The interview guide was developed following preliminary fieldwork during coursework in a qualitative research methods class in the spring of 2001. In this preliminary fieldwork, two parents were interviewed. Revisions to the interview guide from this fieldwork helped to shape the questions for the current study. The interview guide was used in the initial stages of the interview and altered as the interview progressed at the researcher's discretion. To ensure that relevant topics were addressed and that the reciprocity of information unfolded in a natural and fluid manner, open-ended questions and probes were utilized during the interviews.

The researcher served as interviewer as well as maintained the audio taping equipment. Observational, personal, methodological and theoretical field notes were taken immediately following the interview to describe the context and mannerisms that were potentially pertinent to the study outcome as well as personal reflections on the process and preliminary analysis. The interviews ranged in length from 45 minutes to approximately 60 minutes, and concluded when all information was gathered. Additionally, permission was obtained in the informed consent (Appendix G) to contact the participant for additional follow-up questions should this be required for clarity, further exploration of content or to obtain reactions to ideas that emerged in other interviews. Audio taped follow-up telephone interviews were conducted with each participant. The length of these follow-up interviews ranged from three minutes to eleven minutes. Member checking was incorporated into the study by asking participants to review categories, interpretations and conclusions (Lincoln & Guba, 1985). Data for member checking was sent to participants via first-class mail with a return pre-posted, pre-addressed envelope. A total of four case reports were returned from participants with minor changes requested such as removing filler words. In addition, one member requested that a segment be removed due to identifying information. These requests were respected. The case studies were changed per the participants' request. Additionally, final themes and interpretations were confirmed with five of the seven participants via telephone by use of a talking points form (Appendix I) whereby the researcher read major points and descriptive quotations and asked the participants to comment on their particular situation. In this way, member checking was completed. The researcher also conducted preliminary fieldwork with one parent who met the participant criteria. This parent was instrumental in providing feedback to relevance, effectiveness, and appropriateness of each guiding question (Polit & Hungler, 1995). In addition, the researcher was able to elicit feedback as to the effects of the researcher on the participant and the researcher's strengths and weaknesses in interviewing technique and style. Questions for the preliminary participant to consider in evaluating the interview and the researcher's technique were provided to the participant immediately following the interview (see Appendix J) and this portion of the interview was also audio taped. Modifications to the interview guide were made in the form of probes and based on critiques provided by the preliminary participant. Data collected from the preliminary interview was reviewed for quality and clarity of the audio recording. The transcription of this audio recording was included in the final data analysis.

Data Management and Recording

Parent participant responses were audio taped during the interviews. The audio taped interviews were labeled immediately following each interview, and transcribed verbatim. The transcribed interviews were reviewed in detail by the researcher and compared to the audiotape to ensure accuracy of the transcript and to allow the researcher to gain familiarity with the obtained data.

For this study, descriptive field notes were recorded. Field notes served as a depiction of what was observed and contained the who, what, and where of the context under investigation (Patton, 2002). Fieldnotes contained descriptive information that permitted the researcher to relive the observation during later analysis as well as permitted the reader of the final report to experience the activity as viewed through the researcher (Patton). The fieldnotes contained sections for specific use, including observational, methodological, theoretical, and personal sections. The observational portion included observed perceptions of the researcher relating to the physical and social contexts of the interview. It also contained descriptions of participants, the environment, behaviors of participants, as well as communication with the participant before, during and after the interview. Additionally, the observation portion also contained the researcher's own actions prior, during and after the interview which may have influenced the participants' responses. The methodological section contained such aspects as potential participant contacts, contacts with pertinent others such as parent organizations, meeting times, interview appointments, etc. As well, the methodological section also included changes made to the interview guide, problems encountered and how they were solved, and descriptions of decisions that guided the researcher in refining the focus of the study as the study progressed.

The theoretical notes portion contained interpretations of the observations and interviews. This allowed the researcher to draw inferences from the data collected in the field such as interviews and observations for use in the final analysis so that the meanings were attached to the observations (Polit & Hungler, 1995). Additionally, portions of the theoretical log contained excerpts from an electronic bulletin board maintained by the research advisors to assist the researcher in drawing inferences for the final themes of the study. In this way, low-level and high-level inferences were derived from the common categories identified in the cross-case analysis so that relevant meanings could be attached. These bulletin board postings were then discussed in detail with the research advisors as a means of peer debriefing. The final section of field notes was composed of personal notes. This section allowed the researcher to comment on personal feelings that occurred during the study, thereby minimizing researcher bias as described in the self-as-instrument statement (Appendix A).

Data Analysis and Interpretation

Following verbatim transcription of each interview by the researcher, a content analysis was conducted to prepare preliminary categories. An inductive analysis was used to make sense of the data generated from the interviews and field notes (Lincoln & Guba, 1985) and to allow for central themes to emerge from the specific patterns or categories. Transcripts were reviewed line-by line, and coding units were determined according to ideas, thoughts etc. The constant comparative method was then used to collapse and expand the units. Transcribed and coded interviews were cut and slips of paper were then placed into categories according to similar qualities (Lincoln & Guba). Categories made up of slips of coded material were then placed into envelopes labeled with the source of the material, the initial coding units as well as the ending category name. Following this process, categorical lists were compiled using a word processing program. As categories were collapsed and expanded, revisions to the category lists were made. This was also added to the methodological portion of the fieldnotes. Multiple copies of the transcribed data were obtained so that data was available for manipulation and filing purposes (Patton, 2002). Following revisions and refinement of the categories of individual case analysis, individual case reports were compiled to identify pertinent quotations to illustrate the emotionality of the data obtained in the data collection stage of the study.

Information was then combined to conduct a cross-case analysis of common categories derived from each individual case report. Low-level and high-level inferences were then compiled by examining each common category across the cases thereby allowing themes to emerge from the data. Cross-case analysis allowed the researcher to analyze different perspectives on common issues (Patton 2002). At the conclusion of the study, interpretations and inferences were made of the common categories to assist in informing the final themes of the study. Interpretations and themes derived from the individual case reports and cross-case analysis were presented in relation to the initial study questions as they also relate to the referenced literature.

Rigor

Trustworthiness

Trustworthiness of the data and findings from the study was addressed using several methods. A complete and thorough review of the literature was conducted. Research advisors are knowledgeable and skilled in the area of interest and have conducted qualitative research studies previously. Lincoln and Guba (1985) suggest four criteria to increase the trustworthiness of the qualitative study: confirmability, dependability, transferability, and credibility.

Confirmability and Dependability

Confirmability describes the neutrality or objectivity of the data, indicating agreement between two independent people pertaining to the data's relevance or meaning (Polit & Hungler, 1995). In this way, an external auditor, who reviewed the data conducted an inquiry audit by reviewing the data and supporting documents such as the fieldnotes, and determined that the research methods were followed as described in the proposal and that the derived themes were grounded in the data. In this study, the external auditor reviewed the transcripts of interviews, along with the tapes, field notes, and data collection documents collected in this study as well as the cross-case analysis generated by the researcher. The auditor examined the research process at various increments and provided feedback pertaining to the decisions and divisions, and the logical conclusion of the categories and interpretation as well as the justification of such in his professional opinion. This is documented in the auditor's report (Appendix K). In this way confirmability and dependability was judged.

Transferability

Attempting to interview more than one individual per area school district and selecting participants with varying durations of time in the early childhood special education program enhanced transferability of the information generated. Thick, rich description allows readers to compare the results with their circumstances. In this way, the reader can judge the specificity to his or her own situation (Polit & Hungler, 1995) and the confidence that common themes may cut across other participants is increased (Patton, 2002).

Credibility

Credibility refers to the believability in the truth of the data (Patton, 2002; Polit & Hungler, 1995). In this study methods were employed to establish credibility, including peer debriefing, and member checks. Peer debriefing was established by having a fellow graduate student familiar with qualitative research methods review the data and findings as the study progressed. Peer debriefing was conducted at the various points in the study including at the conclusion of interviews to allow exploration of issues, comments on methods, and consideration of ethical dilemmas. Member checking allowed for individual participants to comment on the data and the researcher's interpretation (Polit & Hungler). To establish member checking, all parent participants were given the opportunity to review a summary of the individual case report to clarify meanings and validate conclusions. Individual case reports were sent via first class mail to all participants along with a letter thanking them for their participation and inviting their comments as well as their opinion of the truth of the information. Four of the seven summaries were returned from participants. Only minor changes were identified such as typographical errors and removing fillers such as “like.” One participant did correct one error of fact, changing the frequency of visits from the special education teacher from weekly to monthly. Another participant expressed concern and requested considerable changes in the quoted material. She was concerned about her grammar and that her direct quotations sounded disjointed. The researcher discussed these concerns with her via telephone and explained the nature of naturalistic studies. She agreed to keep the material in its original form, only requesting that a portion be omitted that she felt was too identifying.

Final member checks were conducted via telephone using talking points prepared in advance (Appendix I). Final themes were discussed with five of the seven participants highlighting major points derived from each theme as well as direct quotations from participants as they related to each theme. Participants were given the opportunity to agree, disagree, or comment on the final conclusions as they related to their particular circumstances. Comments were recorded on individual talking points forms. Comments received from participants elaborated on each theme, confirming the inferences but not substantially changing the themes, indicating that saturation had been achieved ant the themes were representative of the group.

Protection of Participants

The study involved minimal risk to participants. Due to the nature of the study, the need to discuss personal issues was potentially emotional for participants and this occurred on one occasion. In this instance, the participant became teary. The researcher responded by validating her emotions and moving to the next interview subject. Participation was voluntary, and participants had the option to withdraw from the study at any time. No participants withdrew from this study. Participants were asked to sign an informed consent form (Appendix G) prior to data collection, and were given a detailed description of the study. In instances where both parents were present for the interview, both were asked to sign an informed consent form. Participants were informed of the purpose of the study and the use of the results in addition to the possibility of publication of the results. Confidentiality was maintained at all times, and participants were ensured of this. Participants' names were changed for transcription purposes, and any identifying information was altered to protect the participants' identity as necessary. Participants were given the opportunity to review a summary of the data and interpretation to ensure anonymity. All data, including personal information, was kept in a locked file cabinet for the duration of this study. Only the researcher had a key to this file. All audiotapes and documents identifying participants were destroyed upon completion of the study.

Summary

There exists a deficit in literature pertaining to parent perceptions of occupational therapy services in early childhood special education programs following transition from early intervention programs. It was important to explore perceptions of parents of occupational therapy services in these settings, as well as the perceived role of the occupational therapist throughout this transition period to gain a deeper understanding of the challenges and stresses that occur for families during this time and to clarify the role that parents perceive the occupational therapist serving in this process. Further, it was important to study parent perceptions related to this topic and how their perceptions changed over time as a result of an extended period of time in the ECSE program. A qualitative research approach was utilized, incorporating open-ended interviews and field notes to provide an in-depth view of seven parents of children with disabilities, whose children attend an early childhood special education program and received occupational therapy services. Further, the research results generated additional research questions for future inquiry.

CHAPTER IV

RESULTS

Data Collection, Analysis, and Presentation

Individual Case Reports

The information presented throughout this chapter was obtained from in-depth interviews conducted with participants. A total of seven interviews were conducted, five with the mother only and two with both parents present. The participants were parents of children with disabilities receiving occupational therapy services in an early childhood special education program. Nearly seven hours (6.95) of face-to-face interviews were conducted, five in the family home and two at the child's preschool. Interviews were conducted using an interview guide and audiotaped. Brief follow-up interviews were conducted over the telephone with each participant to allow the researcher to expand on topics and clarify meanings. Over 200 pages of transcripts were coded, analyzed, and summarized into the seven individual case reports presented in this chapter. Each case report is entitled with pseudonyms assigned to that participant and their child who received the EI and ECSE services. The pseudo names were chosen by the researcher and agreed upon by the participant. The names of others in the story were also changed including other children, therapists and service coordinators to protect their identity. The case report is presented to tell the story of what each family experienced before, during and after the transition in regards to their child's occupational therapy services. Quotations from family members were used as the primary source of information throughout each case report to portray the essence of each family's situation as well as provide the "thick description" essential to enabling transferability (Lincoln & Guba, 1985, p. 359).

Each case report consists of categories that emerged during the content analysis process. During this process, each interview was transcribed verbatim, coded, and analyzed using an inductive, constant comparative approach whereby codes and categories were expanded or subsumed into one another. Following this process, conceptual categories were formed and used to organize each case report and to inform the final themes derived. Categories are presented in italics as a left heading. Not all categories emerged from each interview as the interviews were conducted using an open-ended format, allowing each participant(s) to tell their own story in their own words. Background information is given on each family as well as information to set the stage for the ensuing story. This information was also derived during the interview process or during the initial telephone contact and recorded as fieldnotes.

A total of nine categories were derived from the seven cases. The final categories include fears and feelings about impending transition, preparation for transition, importance, role and benefits of OT, logistics of occupational therapy, benefits of inclusive OT, relationships, feelings and satisfaction, family involvement and participation, contact and communication, and disappointments. These are presented in Table 1, Final Categories, Descriptions, and Collapsed Categories, which include a description of each category and initial categories that collapsed to form the final categories of this study.

Table 1

Final Categories, Descriptions, and Collapsed Categories

Final Category	**Description**	**Collapsed Initial Categories**
Fears and Feelings About Impending Transition	Descriptions of families: initial reactions, fears, feelings, and concerns regarding the upcoming transition from EI to ECSE	● Parental feelings about transition ● Fears of transition ● Information from other parents ● Emotions ● Not emotionally ready ● Involvement of other parents
Preparation for Transition	Activities of preparation engaged in by the family and/or initiated by services providers prior to the transition.	● Role of OT in transition ● Activities for transition ● Ideal transition ● Role of others in preparation for transition
Importance, Role, and Benefits of OT	Descriptions of the perception of the importance, role, and benefits of occupational therapy in the respective programs as well as the role that various members of the EI and ECSE teams served for each participant.	● Importance of OT in EI/ECSE ● Role of OT in EI/ECSE ● Role of others in EI and ECSE ● Support in EI ● Differences between EI and ECSE OT services ● Benefits of OT in EI/ECSE ● Benefits of OT to family
Logistics of Occupational Therapy	Descriptions of the context and temporal aspects of occupational therapy in the respective programs.	● Where OT occurred in EI ● Where OT occurred in ECSE ● Scheduling of OT in EI ● Scheduling of OT in ECSE
Benefits of Inclusive OT	Description of the benefits of including children in a classroom with normally developing peers.	● Locations of OT services at school ● Benefits of mainstreaming ● OT in the classroom
Relationships, Feelings, and Satisfaction	Describes the family's relationship, feelings and satisfaction with the occupational therapist(s) in each respective program.	● Parental feelings about OT at school (ECSE)/EI ● Relationship with OT in EI/ECSE ● Parent control of services in EI/ECSE ● Satisfaction with OT in EI/ECSE
Family Involvement and Participation	Description of each family's level of involvement in occupational therapy in the respective program as well as potential barriers to involvement.	● Parental involvement with OT in EI/ECSE ● Parental involvement in IFSP/IEP development ● Barriers to involvement in EI/ECSE ● Benefits of involvement in ECSE ● Carry over of skills in EI and ECSE
Contact and Communication	Description of each family's means of communication with the occupational therapist in the respective programs. Satisfaction, effectiveness, ideal communication and barriers to communication are also described.	● Contact with OT in EI/ECSE ● Barriers to communication ● Benefits of communication in ECSE ● Work as a team in ECSE ● Ideal communication with OT in ECSE ● Contact with therapists
Disappointments	Describes disappointments that some families experienced with aspects of the ECSE program including disappointments with occupational therapy.	● Disappointments with OT/school system/ECSE ● Feelings about amount of OT at school ● Feelings about inclusion ● Abuse in ECSE ● Hiring practices flawed ● Disappointments and concerns with transition

Wanda and Jeff

Background Information

Wanda was a young mother of three children living in a small subdivision consisting of approximately 50 homes. She was interviewed in the living room of her home while her two youngest children were asleep. The interview lasted approximately 45 minutes and was audiotaped. In addition, a brief follow-up telephone interview that lasted approximately seven minutes was conducted and audiotaped. Her oldest son Jeff was five years old and also present throughout the interview. Jeff's elementary school is located within one or two blocks of her home and is part of a large suburban school district in southeast Virginia. Wanda described Jeff as "autistic" and he also had sensory modulation dysfunction. Jeff attended the ECSE preschool program at the neighborhood elementary school. He was eligible to receive special education services due to a classification of developmental delay although this was recently changed to Autism at a team meeting. Jeff was recently moved to a more specialized tuition based program for children with autism for a half-day program in this same school, and then was transported to a specialized class in another nearby elementary school that served children with pervasive developmental disorder and other related impairments. Wanda shared that the move was at her prompting as she was exploring future placements and wanted what was best for her son. As part of his morning ECSE preschool program, Jeff received occupational therapy and speech therapy as well as services from a behavioral specialist.

Jeff has been in the ECSE preschool program at this same school for approximately three years. The family transitioned to the ECSE program from EI in the spring of 1999, when Jeff was three years old. In the EI program, Jeff received occupational therapy three times a week, in addition to speech therapy, behavior therapy, and participation in a playgroup. Most services provided by the EI program were provided in his home with Wanda present.

Fears and Feelings About Impending Transition

Although in Virginia children are eligible to transition to school based services at age two, Wanda was reluctant: "I guess it was a option for him to go…that September.…I couldn't have done it …he was just so little already…it's not what you're set up for in life…you're not ready to do that."

Wanda was also worried about transporting Jeff to school on a bus, more so than him actually going to ECSE preschool. It happened that her neighbor would be Jeff's bus driver, which relieved some of her initial anxieties:

> I was probably more worried about him riding somewhere than about him actually being in school, I don't know why…maybe just that is a more emotional thing that you relate to, putting a kid on a bus and sending him off…I know there are bus drivers who aren't cautious and stuff like that…had I not had the bus situation that I had, that would have been a major ordeal for me. If I didn't have someone that I knew well before he had to get on the bus…I knew everything about her and she lives down the street from me, that would have been a big hurdle for me; that would have been difficult.

Preparation for Transition

By the time Jeff turned three years old, Wanda was well prepared for the transition by her intervention team. She described the role of her service coordinator in preparing them for the transition:

> I don't think we could have been any more prepared than we were…my service coordinator made sure that all of that [paperwork] happened…There were a couple things outstanding but for the most part everything we needed for [the school system] had already been done because my team knew… Paperwork wise, they got me ready.

Wanda described how her occupational and speech therapist also prepared her for the transition emotionally, by providing activities for Jeff. It is important to point out that Wanda always referred to the infant program therapists and team as her own:

> …My speech therapist and my OT were my two "point guard" people, so they did most of it [preparation]…they had just been talking it up to me for a while…We worked toward it very gradually…The last two or three months that he was in the infant program, my therapists were constantly bringing me things I could work on after they didn't see him anymore. My infant program OT had, months before we transitioned, introduced me to the OT that we were going to have there [school] and made sure that we kind of were acquainted and I knew how fabulous she was. My OT in the infant program probably made me feel better prepared than anybody else I've ever worked with. Wanda also described

how the arrival of her new baby helped her in the transition by providing a distraction:

"When he started school I had a two or three week old baby, so I was distracted, probably at a good way at that point that we had to put him in."

Importance, Role and Benefits of Occupational Therapy

Because of Jeff's sensory issues, Wanda felt that OT was very important for him. She described how the occupational therapist in EI was helpful to her and to her family and the role that the occupational therapist played:

> …We were just starting to understand what his issues were…they were all sensory related, so she kind of had the answer to everything. There were immediate differences in his eye contact and behaviors from when we started OT…they would also teach me how to do it, anything that they did.

As Jeff's sensory issues continued, Wanda also realized the importance, benefits, and role of occupational therapy for Jeff in ECSE by providing sensory integration therapy:

> I think OT is probably the most important thing that he gets…I think he could have six hours of OT a day and that would not be too much…it decreases his stimming, certainly it increases his attention span, he's able to sit longer…finding the right sensory intervention for him just helps him to learn better, they certainly make it easier for him to concentrate and understand…so much of whether or not they're [children with autism] going to succeed depends on whether or not they can focus, and so much of that is dependent on whether or not they have good sensory intervention…a lot of times we can kind of help bring him back to focus through some more intense OT than usual.

Wanda felt lucky that Jeff's teachers in the ECSE preschool were able to assume the role to provide sensory intervention at times when the OT was not working with him: "In the preschool program, teachers did home visits, some of them… and that was always extremely helpful…luckily we have, most of the time, we have had teachers who are very OT…sensory oriented…and they kinda take up that slack."

Jeff's OT services at school were provided by a private contract company that was hired by the school system to provide his occupational therapy services. The same contract company also provided occupational therapy services for Jeff in EI. Wanda felt that having a contract therapist was beneficial because she felt that they were better trained and knowledgeable: "They've always been contracted out…I've not ever had a school-system OT and I think that's been beneficial…they've always been [contract] people."

Wanda also shared that she knew the occupational therapy services in ECSE preschool would be different. She described her views and understanding of the differences in occupational therapy services between the EI program and ECSE preschool program and particularly her concern about interruptions and scheduling changes during therapy at school:

> I saw them, I saw them…they were longer [OT sessions in EI]…no one else was going to come in and walk [in]…nothing's going to happen that maybe [another child] needs to go with them this time because somebody's schedule is messed up…my perception is that his services at home were probably better because I was right here.

Relationships, Feelings and Satisfaction

Wanda described a high level of satisfaction and felt a strong bond with her EI team and particularly with her occupational therapist: "They were a fabulous bunch of people. I was a partner with my infant team…I mean they were like our best friends…she [OT] was the starting point for everything…so she was crucial."

When comparing the two programs, Wanda also shared that she felt her relationship with the therapists ECSE was most different for her compared with her relationship with the OT in EI. She recounted her relationship with Jeff's first occupational therapist in ECSE:

> I think she was a rare breed… I had that really committed, like overzealous OT, who I still felt like I was still in the infant program…I felt like I knew her and I felt like I could approach her so much more than any of the ones I've had since then… she spoiled me.

Wanda was not as satisfied with services in the ECSE program following that first year, many changes followed in Jeff's occupational therapy program such as frequent changes in therapists as well as the quality of the services that he received:

> …With the school system, you know every year, or even in the middle of the year, you have a possibility of things are going to change…I've had four school OT's…I've had two including the one I have now who were really great and really did a fine [job]…and two they didn't get it.

The frequent changes led to much frustration for her:

> I don't know if they're [new therapist] going to be one of those OT's that doesn't think that sensory things are that important…that's the hardest thing for me…I think when I get a new OT every year I don't know if they're going to be up on the new stuff…he regressed developmentally on his goals, and I think that had a lot to do with it.

Differences in the quality of related services Jeff received in the ECSE preschool program was evident to Wanda as well. Wanda felt that the occupational therapy services provided by a contracted company was better than that provided by therapists directly hired by the school system or provided through the tuition based program. Wanda's perception of the differences has been primarily the difference between the qualities of the occupational therapists compared to that of the speech therapists in the ECSE preschool program. Wanda felt that the services that the occupational therapist provided were better than those the speech therapists provided. Wanda was able to judge these differences by the amount of communication provided as well as the methods the therapists used:

> …The private OT's were much better at communicating and more prolific…and also just the methods that they would tell me that they were using whether they were tired and things that I didn't feel were really effective as opposed to things that are contemporary and…new and not something that we tried three years ago [and] it didn't work. I have definitely felt that the OT's were better trained…they were more knowledgeable in current techniques than the speech and other therapists that we've used in the school system. I feel like…the other therapists that were school system employees were…just had less expectations than [contracted therapists].

Wanda also had feelings of reduced control after transitioning to the ECSE preschool; she did not feel in control of Jeff's team or that she had the ability to control his services:

> I feel like I had a lot more control when he was in the infant program because everything happened right here in front of me….I certainly don't have the kind of collaborative team that I feel like I'm in charge of …like I did when I, he, was in the infant program. My biggest concern was with that program was, what I said before, just about not knowing, not being able to control who your OT is. I cringe when I think about changing schools and I think "Am I going to get somebody [OT] up in that school that knows what's going on or am I going to get somebody that, you know, that just wants him to pull putty…for ninety minutes a week?"

Wanda's relationship with the occupational therapists in the ECSE program following that first year was different, as well: "I had absolutely no relationship with them…I know who she is…and I know she does a good job…we're friendly." Wanda shared her feelings about her experiences with occupational therapy in general:

> My OT's have always been much more talented and much more helpful than my speech therapists have ever been through the school system…in the infant program they were pretty much equal.…our OT in my experience has always been the most qualified of the therapists that he's had. My experience has definitely been that the younger the therapist, the better the services I got because they were more open minded.

Family Involvement and Participation

While in the early intervention program, Wanda and her husband were always involved in Jeff's therapies:

> Our family was definitely taken into consideration and we were always encouraged to be very involved…anything they did, they did therapy with him and then I kind of sat and watched…my husband and I were always very involved…There weren't any siblings to involve…they were mostly focused on him.

Since transitioning to the ECSE program, Wanda has had fewer opportunities to be involved in Jeff's therapies. She recounted occasions and reasons for her involvement in Jeff's occupational therapy in ECSE:

> I've been to some sessions at school…on those occasions I just said to the teacher, "hey I want to come and stay and I want to make sure I'm there when his OT happens or when his speech happens."…There were a couple of times where I just was kinda catching up, I just wanted to see what he was doing at school…it was a period where we had a therapist that I didn't feel like we were on the same wave length with his sensory needs so I wanted to observe what was going on in there…there were another couple of times that I felt like we were having some old sensory issues emerge so I wanted to go and see. Sometimes you'll hear, or the teacher will say, "Oh the speech therapist got him to do this or the OT got him to do this," but you don't have any idea how they got him to do that or what the circumstances were…because you're not as involved when they go to school to show you what they're doing, show you how they're, you know [using techniques].

Wanda felt that she would like to be more involved in Jeff's therapies in ECSE and explored barriers to her involvement in Jeff's occupational therapy:

> I don't have the ability with two younger kids to really go to school much…I can't take them into a class and stuff like that or any other session…I either have to pay a baby sitter and it's hard to find during the day…it's just as much my fault as it is theirs.

Ideally, Wanda would like to be more involved in Jeff's occupational therapy at school and shared her preferred level of involvement and her ideal involvement:

> …In and ideal world, I would love to be at his school, you know, I would just love to go for the whole day with him once a week. I would love to see something like a monthly home visit and I think if there was some kind of set time to communicate with your therapist like that, that would make a big difference in you being able to apply what they're doing to your home life. I think that the way it's set right now is probably the best anyone can do.

Contact and Communication

Wanda felt the communication with the occupational therapist in the early intervention program was more open and frequent: "They came to my house…they were here…you know, we talked to them…you called them whenever you want…even after he transitioned I talked; I still called them on a pretty regular basis about things." Following the transition, Wanda felt like the communication with her first occupational therapist at school was wonderful: "I would get a note from her every time she saw him and that was wonderful…she would write in his communication book…something that apparently no one else does…it's never happened since."

After the first year, communication with the occupational therapist at school was infrequent and on a predetermined schedule:

> There's no contact…they've always said, you know, "If you have any questions feel free to call me." I do get progress reports and report cards. I guess I get a little, you know, three sentences from them like every four and a half weeks or whenever that is…communication is difficult.

In addition, Wanda also felt that she had "…very little communications from the school system [speech] therapists."

Wanda viewed the difference in communication with her occupational therapist in the early intervention program and her communication with the occupational therapist(s) in the ECSE program as "[A] huge difference." Ideally, Wanda would love to be more involved in Jeff's occupational therapy in ECSE through "…regular communication…a weekly note in his notebook."

Disappointments

Wanda had many disappointments with Jeff's occupational therapy in the ECSE program. She was very concerned with his sensory needs and felt that not enough attention was placed on hiring therapists that had the skills and experience in that area:

> It's frustrating to me as a parent when the school system is not consistent in their hiring…sometimes you get somebody who understands that and sometimes you don't, and that is a huge flaw in my opinion…I don't understand why anyone would hire somebody that's not an SI [Sensory Integration] OT or doesn't…hasn't gone back to school to understand what that means…I think that's a big injustice to this type of child…I think that there should be some level of consistency there. You should be able to depend on that…if this is the only OT you can get without having to pay ninety dollars an hour for it, you

> should be able to rely on a consistent philosophy in the school system and I don't think they have a philosophy because I don't think they go there…they just hire people and figure you know what you're doing. So I guess that falls back on the subcontractors…these people have all worked for the same company…I happened to only have one OT in the infant program…I could have run into the same thing there, I just didn't.

Wanda also shared her disappointment with the amount of occupational therapy Jeff gets in the ECSE program. She was concerned that he was not getting enough OT and felt that limits were set on the amount of therapy time he received and that his session time was reduced by outside factors:

> The most disappointing thing I can say about OT in the school system [is] that you can't get enough of it…I think this type of disability they need to change the amount that they're allowed to get…I've tried to increase that. I think the amount of OT that he gets at school is probably…I don't know how beneficial it is for him to get two-thirty minute sessions a week…I think he's probably getting twenty minutes of OT at every session there…so certainly there's a time factor. Plus you have to walk from the classroom to the OT room and back so that takes some time [and] sometimes there are outside influences that maybe weigh in on the quality of what he can get on that particular day.

Summary

Wanda's story of the transition from EI to ECSE revealed seven categories. She expressed concerns about her son having to take a school bus at the age of three. A concern that was only resolved because the bus driver was a trusted neighbor. This concern heightened her fears and feelings about impending transition. Wanda described how her EI service coordinator helped her by getting the paper work ready and how her occupational therapist in EI made her feel better prepared than anyone else she worked with, by introducing her to the new therapist and by also bringing her activities to work on at home. These professionals provided a level of comfort for her in the preparation for transition. Wanda placed great importance on Jeff's occupational therapy services both in EI and in ECSE. Occupational therapy provided answers to her questions in EI and allowed Jeff to learn better in ECSE by providing sensory intervention strategies. She felt that occupational therapy was "the most important thing that he gets." She also felt that because the occupational therapists in both programs were employed by the same private contract company, that she and Jeff derived benefits from their expertise and knowledge, benefits she felt were greater than the expertise and knowledge that the school hired therapists offered. She felt that overall occupational therapy services were better in EI because she was there to monitor those services. These perceptions were highlighted in importance, role and benefits of occupational therapy. Wanda described a high level of satisfaction and friendship with the occupational therapist in EI. However, she has felt diminished satisfaction with occupational therapy since the transition that was compounded by the frustration that she felt with frequent changes in Jeff's occupational therapist in ECSE and the diminished quality of his therapists in that program. This led to uncertainty for her that a new therapist will have the expertise in sensory integration therapy that she felt was so beneficial to Jeff. Wanda felt a deep sense of loss since Jeff transitioned to ECSE. She no longer had a sense of a collaborative team with Jeff's OT; she no longer had the ability to control his services;

and she no longer had the friendships that she enjoyed in EI. Her perceptions of these changes since the transition were shared in relationships, feelings and satisfaction.

Wanda was always involved in Jeff's occupational therapy in EI; therapy occurred in her home and she observed every therapy session. She was encouraged by the EI OT to be involved. Her level of involvement diminished since the transition; she no longer had the ability to be involved as much as she wanted. Observing Jeff during OT sessions in ECSE became a concerted effort, with Wanda having to make child care arrangements for her younger children, thus creating barriers to her involvement as depicted in family involvement and participation. Wanda communicated frequently with her EI team; she talked with her OT at every visit and was able to call her anytime she wanted. She continued this line of communication even after Jeff transitioned. In ECSE, she was thrilled to get regular notes from his first OT; it helped her to feel connected. Since that first OT left, she has had very infrequent communication with the OT; communication has been limited to only occasional progress updates. This has left Wanda feeling detached from Jeff's OT at school and wishing for more frequent contact and communication. Following the transition, Wanda has had a chance to reflect and shared her disappointments with the school system and the practice of hiring therapists without knowledge of Sensory Integration therapy. She felt that the school system doesn't have a philosophy regarding the therapists that they hire and not enough occupational therapy services are offered for her son. These concerns are reflected in the final category, disappointments.

Valerie, Chuck, and Casey

Background Information

Valerie was a mother of two boys ages three and five years old. Her oldest son, Casey, was diagnosed with Spina Bifida. Valerie lives in a rural area in Virginia. Her home is set apart from other nearby homes and chickens were visible in her back yard as the interview was conducted. The interview was conducted in the dining area of the family's home. It lasted 58 minutes and was audiotaped. An additional 7-minute follow-up interview was conducted on the telephone and was also audiotaped. Valerie's husband, Chuck, and her youngest son were at home during the interview however; they remained outside during a large portion of the time. Chuck entered the conversation near the end of the interview and agreed to participate in the study. Valerie was a stay-at-home mom and attended to most of Casey's needs, however at the time he was enrolled in EI she was working full-time. In addition to being diagnosed with Spina Bifida, Casey also used a wheel chair and received GI tube feedings. His special education classification was developmental delay.

Casey was in the ECSE program in a nearby elementary school. Casey has received ECSE for three years. He was placed in Kindergarten, however he was moved back to the ECSE program after a short trial. Casey was recently moved to a new elementary school as a result of this change in placement. He received occupational therapy twice weekly as part of his ECSE program and his sessions lasted approximately 30-45 minutes. In addition to occupational therapy, Casey also received physical therapy and speech therapy in ECSE.

The family transitioned to the ECSE program from EI in the fall of 1999, when Casey was three years old. Casey's EI program was primarily conducted through a developmental daycare, which provided childcare services as well as supportive therapies and nursing care. The daycare provided childcare services for children who were typically developing as well. In EI, Casey received two or three sessions weekly of occupational therapy lasting approximately thirty minutes each, in addition to physical and speech therapy and care provided by a nurse who was present in the facility. While at the daycare, the developmental center provided on-site therapies in a separate room and Casey was brought to the therapy room and returned to his class. Valerie explained that the daycare was chosen because it was the only one that could handle Casey's extensive medical and therapeutic needs. Valerie explained her feelings about the developmental daycare and the need for a personal nurse:

> …We were relieved that it was a developmental daycare that had the therapists there and all, I still wanted that medical person there [referring to nurse] in the event of an emergency…he had a monitor he had to wear and everything, so we were really concerned because he had choking episodes and sometimes he would just stop breathing…we wanted reassurance that his medical needs would be [met].

Valerie also explained that it was necessary for her and for her husband to train the staff at the developmental center, particularly the nurse. Valerie shared that they experienced some difficulties with EI, particularly with their understanding of the Individualized Family Service Plan (IFSP), terminology, and understanding why occupational therapy is important in that program:

> When they said my son had to get occupational therapy, you know, I made jokes about it and said, “Ok, he’s going to start a job”…the title didn’t make sense to me. I mean you don’t know what falls under it and they’re the ones that have to define it for us and so far they’ve done a really good job especially in an IEP type program. I saw where a lot of the OT stuff, unless you’re an OT, you have no idea, I mean because it’s a medical, it’s a medical thing, cause they got like the pincer grasp, and some of the techniques. Well after I made the joke somebody started explaining it to me and I still didn’t fully understand I thought the teacher should have handled a lot of that area, but as I worked with the three therapists that had been working with him…I watched and I started to see what the differences [were].

Fears and Feelings about Impending Transition

Valerie and Chuck were overwhelmed with issues that were going on with Casey’s service coordinator and had a difficult time understanding why a transition to early childhood special education services was necessary. Valerie shared:

> …We were still overwhelmed with all the stuff that was going on [issues with service coordinator]…and we weren’t really wanting to do it [transition] anyway because we thought he was getting quite good care where he was at. We didn’t think he was ready and we weren’t ready for him to go to school…we didn’t think he was going to get the care he needed is basically what it was…so we were rather resistant…you always have that fear, Is he going to be understood? Is he going to get the care he needs? Are they going to know what to do when this happens? When that happens? So we had a lot of that fear…whenever we

> switch over to a different setting or different people working with him it always comes up again. We fought it tooth and nail…we were so fearful.

Chuck concurred with Valerie: "We didn't want to do it for a long time, matter of fact, I think we delayed it six months, almost a year." Valerie was particularly fearful and described her feelings about the impending transition. She described that she was not as concerned with changing therapies, but rather him having a medical emergency and no one recognizing the signs:

> Emotionally, I was a nervous wreck. I cried and cried, not in from of him, Casey, not in front of [him], but I was, I was nervous, I was very nervous. I wasn't as scared about the transitioning in the therapy wise…so as far as moving from one type of therapy to another, the only thing that was scaring me about the whole thing was the different people not knowing the signs when he's about to have a medical episode, you know, because there are some minor signs that lead up to it and you can usually circumvent any problem by addressing those concerns before they become and issue. [I was fearful because] he has a lot of medical issues…or they [school staff] don't have that right blend of firm, but nurturing way.

Chuck also described Valerie's emotional state prior to transition as "separation anxiety" and further chuckled as he explained, "She was a basket case…cried and cried."

Preparation for Transition

Prior to the transition preparation, the family's EI service coordinator was dealing with personal issues that interfered with a smooth transition for the family. The situation necessitated a delay in transition preparation and a change in service coordinators for the family. Chuck described the situation prior to the transition: "…We hadn't been told about it [the transition], we had a problem with our early intervention coordinator…didn't give us any information whatsoever, so it kind of delayed it…we weren't, we weren't prepared for it at all."

Following the change in EI service coordinators, preparation activities for the transition began. The occupational therapist (someone the family felt comfortable with) filled in as the family's service coordinator in the interim. Valerie explained how this smoothed the rough start for the family:

> That's where she came in, so she did a fine job, it was just at the very beginning. So, I think she smoothed it over some, but she came in kind of like the last minute, so she was kind of making up for time. But at that point there was a lot of options people were throwing at us and we were trying to decide…and you kind of get overwhelmed and you don't know really what you were offered…With her being his therapist already, we had talked about it [the transition]. Part of her job was doing therapies at the schools, so she had prior experience. She made sure that the proper paperwork was filled out.

Valerie and Chuck further described the role that the EI occupational therapist played in supporting and informing the family as well as exchanging information with the school system personnel:

> She [EI OT/ service coordinator] understood where we were, she understood what we needed or what she thought we needed, and she asked if there was anything more we needed, so she didn't assume that she knew everything, but

> she…helped us to understand the differences that we might encounter, where we needed to be more vigilant. She warned us what to watch for and be cautious about. She had a son that was a couple of years older than Casey, and she talked about his experiences…she helped us, she provided some insight into what we were about to get into. She really gave us a crash course in it and it helped immensely. I think she actually talked to the OT at the school…I don't know if the people there were receptive or not because I didn't really get involved in it.

Chuck described his perception that the EI program was concerned with getting information documented and making Casey comfortable, but wasn't sure how receptive the school system was regarding that matter.

The ECSE teacher was also described as being instrumental in the preparation for transition and also following the transition:

> If it hadn't been for the teacher that we got, it would have been a fiasco…it would have been a disaster. The teacher mainly handled the whole transition in the school thing. I was blessed with the greatest teacher the first two years, she helped me to understand…she helped us with the new "legal speak," the IEP. She walked us through it, she held our hand during the sections that we didn't understand and she would point out issues, but after she gave us the knowledge to work on it…[she gave us] more understanding of what his needs are and where we really need to focus our energy. She walked us through it and she showed us where our concerns were and where we should really take a look at closely.

Valerie and Chuck also described the small role that the EI nurse played in the transition: “She [the nurse] had provided us a book of information about, and she put together a lot of stuff about the switching over from one, so that was helpful too.” Valerie explained how the school staff tried to reassure her during the transition:

> I saw what could happen…in the trenches, but they [school staff], you know they were “OK, we can handle it, we can do this and we can do that and we worked with children at this kind of level…” I think they were focused on getting what was best for him.

Importance, Role and Benefits of Occupational Therapy

Valerie felt that Casey’s occupational therapy services in ECSE preschool were very important for him. She described many skills and tasks that were difficult for him to perform:

> The fine motor skills are extremely lacking for his age group. He needs that extra help to put the pen to the paper to get it where he wants it to be to do the eye hand coordination. If he would sit in front of the task himself [without OT assistance], he would push it away. “I don’t want to do it,” because he knows what it would do to him or how incapable he would feel at the task.

Valerie described her view of the benefits of occupational therapy in both EI and his ECSE class:

> It [EI therapy] was convenient. Having people work with him with a positive attitude helps out because he doesn’t start out feeling like a failure before he even starts…I think he’s become more self-sufficient as he has more therapy.

> [In EI] she [OT] wasn't just focused on [him], she was saying, "How does he do it at home?"

Valerie also described the role of the occupational therapist at school in working with Casey and the benefits that ensued from school-based occupational therapy services:

> Well, I know that occupational therapy involves fine motor skills…at school they kind of focus on the actual tasks that he would be doing at school…and the therapy's there to help him to be at school. She [OT] not only helps him do the task, she's also helping him with the self-esteem. With an OT there, she helps him to overcome that resistance, that fear of attacking something that has a lot of difficulty for him, so she helps…because the whole point of therapy in my impression is to allow him to do the things that others do, maybe not the same way that, his way, and for him to participate just like any other child.

Benefits of occupational therapy in ECSE were also apparent to Chuck and Valerie with Casey's skills at home:

> He's not as resistant to fine motor tasks, self-help as far as dressing, brushing his teeth, stuff like that…he's more open to that. Before he didn't want anything to do with it, pushing it away, but now they're still very difficult for him, but he's not as resistive.

Conceptualizing the differences in the role of occupational therapy in EI and the ECSE class setting was difficult for Valerie because she recognized that Casey's needs changed with his age and development:

> I don't know that I can really say that there's a difference, because I can't, I can't really even throw out the fact his age, his abilities at that certain age…it's really like comparing apples and oranges because of his age difference at the time.

Chuck and Valerie shared that they learned about the differences in the role of the occupational therapist with experience. They conceptualized the differences between the role of occupational therapy services that Casey received in the EI program and that in his ECSE class setting:

> The OT within school focuses on those school tasks and there's things like self help as far as dressing and all that can be done by outside because we don't want him to dress and undress at school…she [OT] can help him put his jacket on and off, do his snaps on his wheelchair and stuff but they're more, more tasks outside the school, functioning. A lot of the stuff at school is basically helping him get around [school]…we have to take him to OT and all that outside of school to get a broader range. I understand that being in the school system I have to make certain adjustments or I have to understand that he's at school, and if he were an average child he would be going to school, and I wouldn't be dropping in and seeing him all the time and I understand that.

A private contract company provided Casey's occupational therapy services at school. Further, Casey's family also sought outside occupational therapy for him, meaning that he received occupational therapy services beyond what is provided through the school system. Therapists from the same contract company provided both

Casey’s school-based and privately funded occupational therapy services. Valerie considered this a benefit to Casey’s overall therapy outcome:

> I believe the [school system] contracts…the people [OT’s] who are working with him do work with the outside contractors…I have faith that I’m not the only one watching over this, that he’s got people…that I trust also looking over their shoulders, so I have…good faith in the therapists…I think that’s a benefit because they can communicate freely and work on how best [to treat him]…if they can’t work on something in school they can communicate that to the outside therapist and [that] way she can pick it up there.…There’s a lot of communication between the two of them [OT’s] so they can talk about how best to serve him…so they discuss Casey and how he’s doing in each so…they confer.

Benefits of Inclusive Occupational Therapy

Valerie and Chuck were particularly fond of an inclusive type therapy model (i.e., receiving therapy in the classroom) and wanted his occupational therapy services provided in his ECSE classroom. They once requested that he not be pulled from class to receive his therapies. Valerie and Chuck described several advantages to this type of therapy model:

> …We promote that they keep him included in the classroom…they used to pull him out of his room a lot…we’ve been recommending, please, you know, time your therapies to coincide with activities that will be beneficial to the therapy itself so that he can be involved in whatever his class is doing…because it involves him in the actual stuff that’s going on in the classroom…she’s [OT]

> just part of the usual classroom setting 'cause he's not the only one she works with…now he's part of the class. It's not a case of "oop" there goes Casey again for therapy, oh he's back now…oh, there he goes to therapy again…so now it's oh, here comes so and so who comes in here a lot [OT]…she comes and goes and she's part of the classroom. I think it's more beneficial in my opinion for them to go into the class and teach him how to do what they're doing, differently if needed…or assistance…so that when the OT's not there, they can still keep going, they [teacher and peers] can still include whatever they're doing and they know…thinking ahead…Casey's going to need this to do it. I think it's more beneficial to get involved in the daily tasks at school.

Valerie and Chuck also saw the benefits of the inclusive therapy model for other children as well as teacher:

> A lot of this, too, kids are picking up on it, the kids are saying, "Well, Casey doesn't have his scissors; let's get those," and pretty soon, they're involved not only in his therapy…but in his playtime, and all that because the kids are trying to help him…but not to the point they're doing it for him. It also helps that the teachers in the system and anybody else that works with him in the classroom itself sees how to help him do it…that's why we don't really like to pull him out of the classroom…we want him to be included…the therapists [are] there to help him do it, but he's still part of the class…he's still part of the environment, the task, he's still participating in class but she's [OT] there to help him with it. So it…doesn't form that barrier between him and the other children…that he has to do things by himself because he can't do them like we can, you know, as far as

> other kids are concerned. I think that by pulling him out it promotes the idea that he's different. That's the whole thing of mainstreaming is change the attitude of the kids as well as the [teachers and staff]…just getting him involved…not that pulling him out [of class] would be disruptive, it would form that barrier between him and the other children.

Relationships, Feelings and Satisfaction

Valerie described a high level of satisfaction with the occupational therapist in the EI program and with that team in general:

> Previously in the early intervention, I was there a lot; we became more open, like a friendship. Being able to work with the early intervention people when I went to pick him up I would meet with the therapists or I'd say, "Hey how'd he do in therapy today?" She [OT] was very open to making suggestions and asking me about what do we do at home. I think it improves the ability to work as a team if you could just casually meet with them and say, "Hey how'd it go, what do I need to stress today, and do I need to talk to him about the attitude, whatever." The [developmental center] people, his therapist and all there, were very good with him and they were good with us and they helped us…they were good people. I had a very good rapport with the therapists…his OT was one of them.

Valerie described her relationship with the ECSE OT as different and lacking the friendship aspect that she experienced in the EI program. Valerie also explained that this did not impact her ability to provide quality occupational therapy for Casey: "…She's nice…there's nothing to do with the actual therapy or her ability to do the job, there's no problem there…she had worked with him [Casey] before and so she had a good working relationship with him."

Valerie and Chuck described their feelings regarding Casey's occupational therapy services in his ECSE class. They described occupational therapists that they felt did a fine job, however there were also occupational therapists with which they were quite unhappy:

> …We had one or two therapists that are no longer working with him for the express reason that their way was… "Do this, you're not doing that, do it, no, not that way" and if you do that with a child you get nothing, nothing. If you get in his [Casey's] face kind of like authoritarian view, he shuts down…they're not using their skills to teach him or getting him to work, they're using just their force of personality and most of the time it doesn't work. But I also have to in some ways have faith in the person working with him knows that this is best for Casey, sometimes you have to as a parent step back and say maybe I don't know the best for my son.

Valerie shared three reasons that she felt were barriers to a good relationship with Casey's OT in ECSE preschool: the inability to meet on a regular basis, that therapists were switched after the school year started, and the inability of the teacher to accept a child's special needs: "I would say the greatest barrier [to a good relationship with the OT] would be a teacher who does not accept the special needs of a child…and to accept help from the therapists."

Additionally, Valerie did not feel that she had as much control of Casey's occupational therapy services in school as she did in early intervention:

> …There's a lessening of control once they go into the school system…as far [as] us having the control to say yes we want this done and no we don't want that done there, we don't have as much control as we did when he was in [EI]. In some ways it is a drawback and I do feel that we need more control…in some ways I do feel that…[I] would like more control.

Family Involvement and Participation

Valerie and Chuck described their involvement with Casey's occupational therapy in EI in terms of picking him up from daycare and casually talking to the therapists about how his session went. They did not often have the opportunity to be directly involved in his therapies at the developmental center although they had the opportunity to see the therapists daily at the center. Valerie chuckled as she described how she dealt with this situation:

> That was the unwritten law that you [therapists] couldn't tell me any of the firsts [developmental milestones], that you had to wait until I come in and say, "Oh you know what he [Casey] did" so then you say, "great" and then you could talk about he's doing it more at school. And I also told them that they're not allowed to do any of the first things he did there. I said when I pick him up I don't want to hear, you know, what he finally did!

Valerie and Chuck explained their understanding of the differences in expectations of involvement between occupational therapy in EI and occupational therapy in ECSE: "I understand that I cannot be in his therapy all the time… I concentrate more on watching what he does in the other therapy [outside of school], so I become involved there, so I focus my involvement there." Valerie also recounted how her involvement with Casey's outside therapy is different from that provided at school:

> …He's not the only one learning when we have his therapy session, I'm learning how to help him with it, like the stairs and getting up and down and stuff. I have to see how they…work any specific task or self help skill, or whatever, so that I can, I can do it with him too...it's not just, "oh you're going to always do that in therapy" because only the therapist knows how to do that or, "I'll show you how to do that."

Valerie has had some opportunities to be involved in OT in ECSE preschool, particularly with meeting Casey's occupational therapists and being involved in the development of the Individualized Education Plan (IEP): "I did speak with the therapist on that [first] day, I met all his therapists and spoke with them personally…as far as actually recommending a task…I haven't done that."

Following the switch in therapists that first year in preschool, Valerie met with the new occupational therapist: "…I met with her again and we talked about things that would help Casey, you know, personal preferences of his and idiosyncrasies." Valerie and Chuck were also involved in Casey's IEP development in ECSE and shared how this involvement was not always well taken:

> …We were very involved in writing it [the IEP], we nit pick it, every little…we get very involved with the IEP. It drives some of the people wild, there's so many parents out there that just drop their kids off and let the teacher take care of it, well teachers "bitch" about that because parents aren't involved. When we get involved, we're so hands on and detailed, it drives them crazy because we're

> the exact opposite of what they [are used to], it really bugs them. Some of them…that last teacher that we just left, she felt it was intrusive that we were not, did not…we just didn't let her take care of it.

Chuck also added that Valerie does most of the talking at the IEP meetings: "She's my mouthpiece."

Valerie also became involved in Casey's ECSE classroom following the initial transition. She accompanied Casey on his first day of school to offer input, particularly with his medical concerns. This level of involvement eased Casey's transition and helped reassure him and eased his anxieties. Involving herself in the first day also eased Valerie's anxieties and assisted the teacher and staff in getting to know Casey, particularly alerting them to the signs that he was about to have a medical episode and teaching them ways to avert that.

Both Valerie and Chuck admitted that they would like to be more involved in Casey's occupational therapy program in the ECSE class and identified potential barriers to their involvement:

> Where school therapy is concerned that's [being involved] very difficult because it's not like I can be there all day long. You've got competing…things going on, one is you trying to do OT, but you're also trying to do school setting, and so it's kind of a double edge sword, you give too much of one thing, he's losing out on another. Where school therapy is concerned that's very difficult [being involved] because it's not like I can be there all day long.
>
> In addition, Valerie identified the classroom teacher as a barrier to her involvement in Casey's occupational therapy at school: "We were not

> encouraged by the teacher to intrude in her classroom so we were kept at the front door."

Contact and Communication

Valerie felt the day-to-day informal communication with Casey's occupational therapist in EI was good. At one point, however, she felt it was necessary to request a more detailed written summary of the tasks they were working on in his therapy sessions:

> …Because at the time I was working, and felt like it was all well and good that he was getting the therapy, but if I was not following up at home, I don't even know what tasks they were offering him…I said, you know, if you'd let me know what you're doing then I can reinforce it at home and we could build on that.

Valerie also recounted one occasion where she had difficulty communicating to the occupational therapist that Casey was having difficulties manipulating the stairs at home. This prompted the occupational therapist to visit their home to get a clear understanding of the situation: "So she came out and she went up and down the stairs with him a couple of times to get an idea of what would be best for him."

Valerie described her communication with the ECSE occupational therapist as good, and felt that it is easy to talk to her and that the therapist was comfortable talking to Valerie, as well. Communication is accomplished primarily by using a notebook "a couple of times a week at least" as personal contact is infrequent. "Sometimes I write a note in the book that we did this with Casey…recommendations for different things.

They write things in the book which is good because it helps me to reinforce it at home and as far as talk about it, as well."

In terms of communication with the ECSE occupational therapist, Valerie shared that in the past, with a previous occupational therapist in the school system, communication was infrequent and that it affected their team relationship. However, since changing schools recently, communication with the occupational therapist has improved. Valerie also mentioned that meetings with the occupational therapist occur impromptu such as when she drops Casey off at school. There have also been infrequent phone calls with the occupational therapist. Valerie was pleased with the frequency and means of communication with the occupational therapist at the time of this interview. She frequently used what the OT wrote in his notebook to work with him at home as well as to let his other (i.e., privately funded) therapists know and to "keep the two therapists working together with him." Ideally, Valerie would like a summary following each occupational therapy session: "I would prefer a summary of each therapy session, to give me an idea of what tasks were asked of him, how well he did them, and ways I might keep it going at home."

Valerie explored barriers to effective communication with the occupational therapist in ECSE such as limited time on the therapists' part, an uncooperative teacher, and the lapse of time between calling a meeting and it actually occurring:

> I'm not there all day so I don't know what he does…but I still need to know what he did so we can talk about it and keep it going at home. I know everybody wants to meet with all of them [OT's] so it's kinda difficult for them

> to meet with them every time. I mean I could call a meeting, but by the time you call a meeting the issue is probably over.

Disappointments

Valerie and Chuck had many disappoints with Casey's occupational therapy in ECSE. They described what they felt was a poor therapeutic relationship: "The OT, I think the one that had the abrasive way with her and with Casey, I think she was with him that first year, so she…basically she didn't work out." Another ECSE occupational therapist was not receptive to information from the EI therapists:

> Lilly [the EI OT] had worked with him [Casey] for years, and this other one [ECSE OT] didn't know him from anybody, and you'd think that she would want to, but it didn't appear to be that way…it's kind of like "this is my world that he's in now, so do as I say"…and [she] had the attitude, "well I know what I'm doing and so why are you telling me anything"…yeah, I thought it was kinda inappropriate because you're trying to help a kid, you're not trying to…step on anybody's toes. Yeah, because you had a lot of…her trying to give a lot of information and the other one wasn't really too receptive because they work for two different companies and they compete for contracts.

Valerie and Chuck also expressed disappointment with the transition, particularly with the school system from which Casey received his ECSE services:

> I didn't think that the school had near as much interest in the switchover as the [developmental] center…and with the school it was like, it was kinda like a "half-ass effort"…he was more trouble than he was worth evidently to them. Because it takes months for them [school system personnel] to learn it

> [techniques for treating medical issues]…a lot of them…they don't have the extra drive to learn it…they don't give him the care we think they should, [and did not provide] us the information we felt we needed.

Valerie and Chuck also recounted what they felt was an abusive situation in Casey's ECSE classroom this school year. This resulted in a change of schools for Casey:

> The school that we just moved out of the teacher made remarks to me…she was angry at Casey for his inability to perform fine motor skills. She was abusing him, not physically, emotionally and spiritually, and self-esteem wise she was just tearing him apart little by little…. That kind of attitude in the school system makes OT so much more difficult; makes anything so much more difficult.

Valerie and Chuck also shared their disappointment with the transition on the part of the early intervention program:

> I think they [EI program] had an agenda of their own because we were paying them to keep him in there and it was not only daycare, but they were getting the therapies and if he had gone to school [transitioned sooner], they would have wound up losing all that…so they would have…lost a good chunk [of money].

Summary

Eight categories were identified in Valerie and Chuck's case. Valerie and Chuck were very resistive and expressed fears of Casey having a medical emergency in ECSE. They couldn't understand why a transition was necessary when Casey was already getting the care he needed in EI. These concerns were heightened when a problem arose with the EI service coordinator, necessitating a change in coordinators.

These concerns were highlighted in fears and feelings about impending transition. Various professionals were instrumental in helping at different phases during the transition. The occupational therapist served as the service coordinator for the family during the initial transition and provided a level of comfort for them. She was able to provide the family with insight and understanding that helped to pave the way. The ECSE teacher walked them through the process once Casey started ECSE and gave them the knowledge they needed, thus also helping the family in preparation for transition. Valerie and Chuck viewed Casey's OT services as very important in both programs. They described a clear understanding of the role of occupational therapy in Casey's ECSE program and expressed that OT focuses on tasks to help him function in school. They understand that school based services can't meet all of Casey's needs, thus they seek privately funded services to get a "broader range" as described in importance, role, and benefits. Valerie and Chuck wanted Casey to be included in his ECSE classroom; to be involved in what the other children were doing. They felt a barrier would be formed between him and the other children by taking him out of his classroom for his OT sessions. This allowed therapy to continue throughout his school day rather than just when he had OT, highlighting the benefits of inclusive occupational therapy. Valerie felt a strong friendship with Casey's therapists in EI, a relationship she has not shared since he transitioned. Valerie and Chuck described therapists in ECSE that were authoritarian and counterproductive to Casey's success in school, emphasizing both positive and negative relationships, feelings and satisfaction with the occupational therapists that worked with Casey.

Valerie accompanied Casey to school on his first day of ECSE. She alerted the staff to signs that he was about to have a medical episode and teaching them ways to avert an emergency. This high level of family involvement and participation eased the anxieties that both she and Casey were experiencing toward his first day of school. Valerie described how her communication with Casey's therapists has changed since the transition. In EI, she enjoyed daily conversations with the therapists, however they were not always detailed enough for her. Since Casey has had numerous OT's in ECSE, she has had to adjust to each therapist's style, but felt that using a notebook consistently satisfied her need for contact and communication. Chuck and Valerie reflected on the transition and felt that there was resistance on the part of the occupational therapist in the ECSE program to accept information about Casey from the EI OT. They felt that these feelings of resistance stemmed from the therapist's working for competing contract companies. This unwillingness on the part of the ECSE staff added to their list of disappointments with the transition.

Kevin, Lisa and Chris

Background Information

Kevin and Lisa were the parents of three children, two young girls and the youngest, a son, Chris. Chris was four years and ten months old and was experiencing developmental delays at the time his parents were interviewed. Kevin and Lisa lived in a neighborhood of approximately 200 homes, all constructed approximately within the previous five years. The interview was conducted in the dining area of their home and lasted approximately 56 minutes and was audiotaped. In addition, a follow up interview was conducted over the telephone and lasted approximately six minutes; the telephone interview was also audiotaped. A view of the family backyard was visible from the location of the interview so that the children could be closely watched. The backyard consisted of a trampoline and swimming pool, which kept the two girls occupied. Kevin did frequently leave the table to check on the children, answer a question or write a response to a note from one of the girls. The two older girls played outside primarily, however they came in and out throughout the interview. Chris was also present throughout the entire interview and was occupied in the living room area of the home most of the time.

Kevin and Lisa were concerned with Chris' development from the time he was very young and his physician finally confirmed their suspicions. When he was nine months old Chris was identified as having a developmental delay. At the time of this interview Chris did not have a definitive medical diagnosis and the family continued to seek the advice of specialists in order to secure a definitive diagnosis and help for their son. Services in the EI program began for Chris and his family when Chris was approximately one year of age. In EI, the family received service coordination services as well as physical, occupational and speech therapies. Occupational therapy services in EI included three weekly sessions of approximately forty-five minutes duration. Chris received services at a developmental day center one day a week that included childcare services as well as his developmental therapies. On the remaining days, Chris received his therapies at home. This schedule worked well for the family as Lisa worked Monday through Friday and Kevin worked a rotating schedule in medical professions, which allowed several days off during the workweek. Lisa expressed concern that, if they lived in a different county, the developmental daycare would not have been an option for them.

The family transitioned to the ECSE preschool in the fall when Chris was two years old. At the time of the interview for this study, Chris was completing his third year of ECSE services at a local elementary school. He continued to receive services due to a developmental delay, which Lisa describes as “uncoordinated [and] can’t talk.” Chris received physical, occupational and speech therapy in this program as well. His occupational therapy services included three-thirty minute sessions each week when he transitioned and was reduced to two-thirty minute sessions per week this school year. Further, during his three years of ECSE, Chris has had two different occupational therapists.

Fears and Feelings About Impending Transition

Kevin and Lisa were comfortable with their decision to transition Chris to the public school ECSE program at the age of two. They had to decide if they wanted him to stay in the early intervention program for another year, and ultimately decided to “go a year earlier.” They felt that it would be beneficial for him to be around other children that were not disabled so that he could observe “some model students.” Lisa shared that she felt emotionally prepared for the transition, and felt confident that his therapies would be adequate. They shared their feelings prior to the transition:

> We knew he would still receive services…the only question we had was…how often would he get the services, what would they be working on, and would they carry over what they were doing in the early intervention to the preschool program…they pretty much answered those questions for us when…we asked

> them. We were pretty much accepting and pretty adjusted to it [transition] or else we would have just kept him in early intervention for one more year. What we weren't prepared for though has nothing to do with his therapies, it's just going into a public school system.

Kevin and Lisa also described their fears with regard to Chris' transportation to school at age two:

> Our only fear was because he couldn't talk and he was going to school, it's like how do you know if something's going to happen, he can't tell you…he was only two…[riding] the bus and going to school is a lot different than just going to daycare. Like I said, my…only fear was sending him off on the bus when he couldn't talk and I'm like 'he's only two and are you sure it's going to have a car seat and how's he gonna sit on the bus'…it was just you know tiny things like that.

Lisa and Kevin told their story of how their worries about transportation led to greater fears once school got started:

> …We had a lot of problems with his bus when it first was coming and Kevin was calling and complaining at transportation and I'm like, "Don't go and complain because they could be mean to him on the bus and we won't even know."…cause they wouldn't come till ten after nine to pick him up and he was supposed to be there [at school] at nine, and he called and I'm like, "No, don't call and complain…the assistant could beat him on the bus and we wouldn't know the difference."

Lisa and Kevin were also worried about how Chris would eat at school:

> …He couldn't feed himself at the time, I'm like "oh my God how's he gonna eat at lunch time, are they gonna feed him, what are they gonna do"…they didn't tell us that in the preschool program they stay in their classroom for lunch, we're thinking, OK he's going to go to the cafeteria, he's going to sit in front of the tray…how's he gonna eat?

Preparation for Transition

Following the decision to transition at age two, Kevin and Lisa began transition planning activities. The early intervention service coordinator handled most of the preparation for transition and Kevin and Lisa described her role:

> She was preparing us for [the] transition and we really didn't have to do it at that time frame, it was our option and we took the option and so she explained it to us. She explained to us how the transition worked, age of eligibility…she …informed us of what would happen, how the transition would work…services he would receive there and that it would just transition from early intervention to preschool. …She just let us know what dates were available and she even did the scheduling of…when we could do that eligibility and all that stuff.

Kevin and Lisa also described their experience with the eligibility meeting during the transition:

> Let's just say we had that "big pow-wow session" where the center's [EI] therapists met with the school system's therapists and they kind of put their heads together and…they told us basically what he was going to receive. We had a big session with everybody…like the school psychologist and all the teachers…they made it sound just like he was going to get the same

> services…we asked a lot of questions when brought up, especially her [Lisa], bombarded them with the questions and they answered all the questions that we had…to our satisfaction. Yeah it helped us to identify who…all the people were that he was going to be working with.

Prior to Chris receiving EI services, Lisa didn't know the school system would provide therapies:

> …To be totally honest before Chris started getting therapies and stuff like that I didn't have a clue you could even get that stuff through the school…I didn't know they ever did like physical therapy and occupational therapy and all that stuff at school.

The school system also held informative programs and classes for families transitioning to ECSE such as Understanding Special Education (USE). Kevin and Lisa attended these programs and found them helpful in their understanding:

> …They had a program where they had "Meet the school system" and you could go and they had therapists and different people from the schools there and then they also had…[a] "Understanding Special Ed." class that we went to that talked about different things to expect in school.

Kevin and Lisa also described the role of the occupational therapist in the transition preparation. They described a collaborative effort from both the early intervention therapist and the therapist from the school system that included a collaborative evaluation as well as sharing therapy notes:

> I don't know exactly when they met, but …what they did when we did his IEP they, they talked about what he had been doing and working on and what they

> felt he need[ed] work on further…they were on the same playing field. I think she did an evaluation with the school occupational therapist.

After the eligibility Kevin and Lisa were left feeling that everything was done and ready, particularly in terms of occupational therapy. When asked if the OT could have done anything differently or better in the transition, they replied:

I don't think so…the therapist there was really good, kept us well informed on how to do things, gave us ideas and suggestions, she was, so it didn't really leave us as far as questioning as though what will happen.

Importance, Role and Benefits of Occupational Therapy

Kevin and Lisa explained why they thought occupational therapy was important for Chris in ECSE preschool:

> I think it's extremely important because it teaches a lot of his life skills…like with brushing his teeth and feeding, drinking, and things of that nature, so to me it's extremely important that he learns those types of skills other than just…the general educational things and the fine motor and gross motor things that go along with physical therapy.

Kevin and Lisa viewed the role of occupational therapy in both the EI program and the ECSE program as similar. They described what they felt the role of occupational therapy was for Chris in the EI program:

> He had problems with…he kept his thumbs in so they got him a little sort of pseudo glove that kept his thumb out. They worked on a lot of stuff with his fingers and hands…how to grasp, grasp things, building blocks, try to put things together…she worked a lot with the PT as well because he was really behind in

> his gross motor skills. Not only was she extremely helpful in getting his therapies and his skills, but also explaining that to us, allowing us to watch and giving us information to work on at home with him, so she…was a really good influence on what we should see and expect, and things that we could work on to continue on with his therapies…they actually instructed us to work with him to try to grasp an object and…work on switching [hands] back and forth. They gave us some things to try to work with at home.

Kevin also explained how the OT gave them instructions on how to work with Chris and how to tell his siblings the same things so that they could be involved and work with him, as well. Additionally, Kevin and Lisa felt that OT in EI was beneficial because Chris carried over skills from occupational therapy while in EI and improvements were evident:

> …He tried because when…he started [OT]…he wasn't rolling over; he wasn't sitting, so a lot of that stuff we see him trying to do at home after they were working with him. …It's hard to see the improvements as minor as they are, but outside, outside people, friends, relatives would notice the difference more so than we would. I thought it was beneficial because they…worked with him to do things he wasn't able to do before or wasn't doing before, trying to bring him up to more of his age level than where he was. The scheduling was real flexible, they basically said whatever days or time worked best for us and that's what we went with, so they were real flexible on that and trying to accommodate our needs. I think it kinda worked out good because we were here, whereas at the center we didn't go to watch, so we could kinda see what they were working on

> and try stuff like that at home. Plus there was the comfort level being as young as he was and as behind as he was, I felt uncomfortable sending him away somewhere.

They also explained their view of the role of occupational therapy in his ECSE preschool, the context of his therapy, and the tasks that were addressed there during occupational therapy:

> They have a special therapy room…the sessions occur in separate trailers. Sometimes [the therapist] will come over and do some in-classroom kind of like a group OT with all the children but the majority of the time I know she takes him out from his classroom…where it's just one-on-one. His current occupational therapist she works a lot with his life skills. I know she's working real hard with him right now because he has a hyper-gag reflex…brushing of the teeth and the oral stimuli, things to overcome that…she gave us quite a bit of information on how to assist with that over the summertime before he goes back to school. With him being in the preschool program they're still focusing on the basic stuff like they haven't gotten, I don't think, to holding a pencil and things like that cause they're still working on…his grasp is still raking, and so they're still working on and holding the spoon and the basic things like that and not quite school stuff yet. But this year we've noticed, too, OT's been working a lot with the speech doing like some oral motor stuff, like trying to brush the teeth and things like that…holding a cup, holding a spoon…brushing the teeth, doing more like the ADL type thing.

Kevin and Lisa also explained that they felt that the role of the OT in ECSE might be beginning to shift for Chris: "…It's tending to shift some now, I mean they're not so much doing the basics as they were earlier cause he's met those milestones and he's older and he's caught up some, but not completely."

In addition to the role of the occupational therapist in the ECSE preschool, Kevin and Lisa highlighted the role of the ECSE teacher in maintaining Chris' therapy schedule:

> …The teacher has a board up there with the daily routine for the kids and then she has …a monthly calendar and she writes the children's names in…speech therapy is blue, occupational is green and physical is red, and she'll write their names up in that day so she knows exactly what day it is.

Kevin and Lisa were also able to recount benefits of occupational therapy in ECSE preschool for Chris:

> He pretty much can feed himself independently now, holding the spoon appropriately and he can drink out of a cup with a sippy lid, there's still some difficulties with it, but overall…using the spoon and a lot of feeding skills…just we don't have to feed him every dinner.

Kevin and Lisa had some difficulty identifying differences between occupational therapy services in early intervention and what Chris received in early childhood special education:

> I knew they were gonna still be working on a lot of the same things and the idea for the preschool I think was to try to work on things that he still had problems with getting ready to go to regular school.

Relationships, Feelings and Satisfaction

Kevin and Lisa were very satisfied with the services in the EI program. The same therapist provided services the whole year that they were in the program. They described their relationship with her:

> It was pretty good…she was the one who suggested the glove and was looking for different things to let us know what to do to help him out and try to make him…do the stuff that she wanted him to do she was, she was pretty good. Actually, she's still at the [developmental center] where he goes to daycare and she keeps in touch.

Kevin and Lisa also felt satisfied with the occupational therapy that Chris received in the ECSE preschool:

> I'm satisfied; I believe they're working hard with him, making progress. The first therapist he had was really good, she was really into …sensory stimulation and stuff like that and she did a lot with him like on …a little swing, standing on this little trapeze little swing. OT's been working really well with him, I've, we've noticed since being in school there's been a significant improvement over the three years, he's done quite a bit that he wasn't able to do before, but there's still a lot that he can't do and they're still trying.

They described their relationship with the two occupational therapists Chris has had in the ECSE preschool:

> The first one we were, we were really on really good terms with, in fact when we would see her out some where…she really liked Chris, and I think because like we said she was into that sensory stimulation thing and he was like the

> perfect kid cause he needed all that stuff. And this one [current OT] I think Kevin's more, has more of a relationship with than I do because I have only ever seen her once; I didn't even know what she looked like until like a couple of months ago. I've met her once [and Kevin] met her twice.

They also described their feelings about the occupational therapists in ECSE preschool and how their feelings about the first therapist prompted them to acquire her services over the summer months:

> …The first one really liked Chris because it was a true challenge for her…to her he was a challenging student, but also one that you could get measurable progress from, so she really enjoyed working with him cause she could see the results of her own work…we signed him up for therapy with her last summer, and she did…OT therapy over the summer with him. Now as far as the new one, [we're] still trying to figure her out.

Family Involvement and Participation

Kevin and Lisa were involved in Chris's occupational therapy in EI, both at the center and in their home. They described their level of involvement:

> We tried to involve as much as possible…[we] took him to therapy and waited till he was done. We kind of participated and helped…we'd sit with him and help, try to help him build the blocks a lot of times.

They also identified Chris' behavior as a barrier to the family's involvement with his occupational therapy sessions in EI:

> We tried to do as much as we could but when he would start being real uncooperative and looking to us we would have to leave, otherwise the session

> was over. …It wasn't because of the therapist it was because of him, I felt like I wanted to do more and participate more, but I was unable to because if I did he wouldn't do anything…by removing us from his sight he actually performed better…he just wouldn't do [his] therapy sessions if we were there.

Kevin and Lisa were also involved in the development of Chris's IFSP while in the EI program. They described how their involvement was commensurate with their level of understanding at that time:

> I think it was…a big meeting with the service coordinator and all the therapies…and that's when they gave us their results of…their testing and where he was…and they [said] what they saw as goals and objectives and what we wanted as goals and objectives as well. …They looked at it more of what they felt was necessary for him to achieve versus what we wanted to see as milestones for him to achieve, so there's a little bit of a difference there because we would say, "yeah we like that but we want this as well"…it was more with the …motor function like with the PT because she did a lot of balance stuff that we really had no clue about like sitting on one of those boards…we wouldn't have put anything in there because we didn't know that he was unsteady and things like that.

Kevin has had some opportunity to be involved in Chris' occupational therapy at school:

> I actually went one time to observe, just to see what they were doing…I just happened to catch an OT session…they invited me to come over and watch and

> I said, "well, OK, but I'm going to have to hide" that's what I did, I hid around the corner to watch.

Lisa and Kevin also recounted how the school OT tried to involve them with skills for Chris at home:

> …The past couple of times I've met with her she says some of the things that she does.…She's mentioned, "you really should make sure you do the teeth brushing thing every day cause I've really been working hard on it."

The development of the IEP also gave Kevin and Lisa the opportunity to be involved in the ECSE program:

> I was very involved…we told the therapists and the educators not only what they wanted to see or have done, but what we wanted to see and [have] done and some accomplishments and goals that we would like to see…and the milestones that we'd like him to see and the timeframes, so we played a big role in doing that. We weren't just going to sit there and let them tell us what they were gonna do. We're pretty assertive and stubborn on our choices.

Lisa also took the initiative to draft an IEP:

> …for Chris' IEP they're going to do next month, I basically, I took his old IEP and looked at every topic and I practically wrote the whole IEP and I sent it to school and the teacher's like, "great, this is what I wanted," I [said] well, I wanted to make sure what I wanted got on there.

In addition, they felt that their professions in the medical field helped them to be involved and understand more of the IEP and the goals and objectives that went into it: "…We know a little bit more than like the average parent and I think that helps out a little…where a lot of other parents don't know about that stuff…it's like…nursing care plans for my patients." Their involvement with ECSE OT is also evident in the adaptations that they make at home:

> [He] has to still use a bowl, he can't use a plate because he looks for the edges to push the food…we use the wide rim type soup bowls…[we use] non-skid and we put it so it [the bowl] doesn't slide.

Kevin and Lisa expressed that they would like to be more involved in the occupational therapy in Chris' ECSE preschool and identified aspects that they viewed as barriers to their involvement such coordinating therapy with their work hours and lack of feedback from the therapists:

> I'd probably like to be more involved, but it's a little harder just because they do it during the nine to one [hours]…that time isn't always good with us working and things like that, it's hard to coordinate whereas the early intervention we could say alright, we'll be home a three so let's have it at three-thirty type of thing. …I've just never taken up on the offer [to observe therapy] cause one we have to try and figure out exactly what days and times. …We don't really get a whole lot of feedback and that's…frustrating.

An additional barrier to their involvement is Chris himself: "…At this point and stage you really can't because he just won't do [therapy] for us like he will for others."

Contact and Communication

Kevin and Lisa were satisfied with the level of communication with Chris' OT in the EI program. Their communication was primarily verbal, following his therapy sessions both at the center and in their home:

> …After the session was completed she'd pass any pertinent information or what she worked with on with him that day…she would just explain what she had done and what we could work on at home to try to improve…if we had any questions or concerns she answered them right after his therapy and any time in between…we could easily get a hold of her by phone.

In addition to the verbal communication, Kevin and Lisa also received activity packets and instructions and activities in writing from the occupational therapist in the EI program. They also received updates of his IFSP: "I don't think we really had any like notebook or anything like that…we just always got a copy of his IFSP…so it might have been every…six months."

Kevin and Lisa felt that the handouts that they received from the occupational therapist were beneficial, however they didn't always feel that the things on the handouts were always attainable for Chris:

> …Some of the things…we just felt that he would not be able to accomplish because as far behind as he was…we would have loved to meet those goals but we didn't feel he'd be able to be or do it, not to say that we didn't try, but…

Kevin and Lisa were not as satisfied with the communication with the occupational therapist in the ECSE preschool, although they did believe they could access her if they needed to:

> …As far as communicating, she doesn't communicate as much as the previous, I mean in the school based as the early intervention, there's not as much communication just because we [don't see them] as often, they're not doing home based, it's more school based. We don't get like every time he has

> therapy we don't get a report, it just happens to be if they did something significant or the mood strikes her or we write something…and then they'll write something…we don't get many notes in the book unless we specifically ask…he has a daily notebook he takes to and from school.

They shared that there was not many notes received the current school year from the occupational therapist. Primarily, communication about occupational therapy comes through notes from the teacher: "…she [teacher] will say…he was at therapy today or something like that…it's more of his teacher…will explain whether he had a good day/bad day but nothing really explaining the therapies." They also explained how initially in the ECSE program they received regular progress reports, but that has since changed:

> In the school system, when he first started…he would get a progress report from school but then the school system changed the way they do it and we don't get the progress reports anymore, which I kind of liked it because then you kinda knew what was going on.

Kevin and Lisa also shared their perceptions of the differences in communication between the EI program and the ECSE program as well as their ideal communication with the occupational therapist in ECSE:

> The early intervention I think we had greater communication just because we were [in] more direct contact…[at school] there's not as much contact between the two of us because he's going away from us, going by bus…he's in a classroom setting. If they could…just tell us a little more of what she's [OT] working on specifically and how she's doing it maybe we can try to do the same

> goal…at least…monthly if quarterly, just some sort of progress to measure, kind of like when kids get report cards…just to get a basic progress report on how he's doing, what goals or objectives he's met, or what different ones they feel the need to [work on or add].

Summary

Six categories were identified within the information that Kevin and Lisa provided. They expressed their concerns about transporting Chris on a bus at the age of two; fears that were compounded when they had to complain about the bus services. These concerns heightened their fears and feelings about impending transportation. Kevin and Lisa attending an informative meeting where they learned about the services Chris would receive in ECSE, prior to this, they did not know that the school system would provide developmental services such as occupational and physical therapy. This informative meeting helped to comfort them in preparation for transition. Kevin and Lisa shared that Chris' occupational therapy services were important in both programs. They viewed occupational therapy as assisting Chris with developmental and other "life" skills; skills that he will need beyond the general education skills that are typically associated with school. These expectations captured the essence of occupational therapy for this family in importance, roles and benefits of occupational therapy. Kevin and Lisa were satisfied with the occupational therapy services Chris received in both the EI and ECSE programs. They formed relationships with his therapists that were quite different. His first OT in ECSE left them feeling a genuine sense of caring and concern, enough that they sought her services over the summer months when the school system did not provide therapy for Chris. These relationships were highlighted in relationships, feelings and satisfaction. Kevin and Lisa wanted to be involved in Chris' occupational therapy sessions in EI and in ECSE, however Chris did not always cooperate during the sessions and became distracted with them in the room. This resulted in them having to take on an observer role when they really wanted a more active role in his therapies. This barrier diminished their level of family involvement and participation. Kevin and Lisa felt a sense of diminished communication in the ECSE program since the transition. In EI, they talked to the OT after every therapy session, getting explanations and activities they could work on at home. In contrast, they are left to wonder what Chris is working on in OT in ECSE; they are disappointed in the lack of information and contact with his OT. Kevin and Lisa discussed their diminished satisfaction with contact and communication.

Hiedi and Michael

Background Information

Hiedi was the mother of two boys, ages seven and three. Michael, the youngest, had Down syndrome and was experiencing developmental delays as a result of his diagnosis. The interview with Hiedi was conducted in private at Michael's preschool, in a small room used as the school's library. The interview lasted approximately fifty minutes. Further, a brief follow up telephone interview lasting approximately four minutes was conducted and audiotaped further explore areas of interest and to clarify Hiedi's responses during the initial interview. Hiedi was aware of Michael's diagnosis since his birth. He was born in another state and received EI services there from the age of approximately three months. His EI services at that time did not include occupational therapy, but rather consisted of a home visit by a sole provider for an hour each week. Following the family's move to Virginia when Michael was one year old, the EI program in their county evaluated him and determined that occupational therapy services would be beneficial. He then began receiving thirty minutes weekly of occupational therapy services in his home as part of the EI program. In addition to occupational therapy, Michael and his family also received physical therapy weekly for forty-five to sixty minutes, as well as speech therapy services once weekly for thirty to forty-five minutes.

Michael's EI program also consisted of monthly visits from a special education teacher who also served as his service coordinator. In addition, Michael participated in a weekly group at the EI center that was led by a special education teacher. The group included up to eight other children with developmental delays and centered on a theme for each month as well as other developmental activities such as gross motor and fine motor play and sensorimotor activities.

Hiedi was primarily concerned with Michael's feeding difficulties while in the EI program. He was also experiencing difficulties with grasping that were addressed by the occupational therapist: "I think that was the main initial issues…feeding, drinking…food textures, swallowing, [and] his finger grasp." At some point in his EI experience, the speech therapist and the occupational therapist combined therapies to facilitate Michael's cooperation.

The family transitioned to the ECSE program in the fall when Michael was nearly three years old. They decided to start him in September when the school year officially commenced, although remaining in the early intervention program until he reached three years of age was an option for them. Michael continued to receive ECSE services under the classification of developmental delay. Hiedi and her family were interested in seeking an inclusion preschool experience for Michael and ultimately decided on a special inclusion program in their county that allowed preschoolers with developmental delays to attend community preschools. Supportive services such as developmental therapies and support by the special education teacher was provided at the preschool site by the local school division. Tuition for the preschool was provided in part by a special fund supported by community volunteers and various fundraisers. Hiedi was also responsible for a portion of the preschool tuition.

Inclusion preschool was considered Michael's early childhood special education placement. In this program, Michael was assisted by a special education teacher who also acted as his service coordinator within the ECSE program. She assisted him in his classroom three times a week and provided home visits twice a month to "play with him and show me little things to do." At the time of this interview, Michael's teacher was on maternity leave and no one assumed her responsibilities in her absence. In addition to the special education teacher, Michael also received occupational therapy twice a week for thirty minutes, speech therapy three times a week for thirty minutes, and physical therapy once a week for thirty minutes. Michael has had the same occupational therapist since the beginning of the school year. Monthly team meetings were also held at the school and attended by his parents, therapists, special education teacher, classroom teacher, and the school director.

Fears and Feelings About Impending Transition

Knowing that the transition was upon them, Hiedi remained initially resistant to the transition. She described how she felt emotionally prior to the event:

> At first I didn't want to leave it [EI program] because I was comfortable with it…it's daunting…it's "scary" when you move, leaving something familiar to go someplace new…it takes a few times for that to "soak in" because it's all a foreign, the whole procedure is not known to newcomers to this "club" of disabilities.

Hiedi spoke to other parents, whose children previously attended the inclusion preschool, prior to Michael's transition to ECSE and this also added a level of comfort for her. She particularly spoke about the therapy aspect of the transition and how she was comforted by what other parents had told her: "Knowing what I heard from other parents that these therapists are good and they know what they are doing…I felt I could trust them."

Preparation for Transition

Hiedi began making preparations for Michael's transition following the decision to transition him before he was three. Various programs and activities were available to her to help her family make informative decisions about inclusive preschool and ease them through the transition, including Partners in Policymaking, a program offered through the state of Virginia:

> We had been to a few seminars [that said] that inclusion…for my son's type of disability, it is really important. They really seem to blossom. My husband also had taken POL, Partners in Policymaking…it's a program funded by the state of Virginia for interested people and it's in Richmond. The special education [department], they gave a [class]…on IEP's or something, and they had a list of [inclusion] program preschools.

Hiedi and her husband decided that they wanted an inclusion program for Michael's preschool experience. She told why this was important:

> An inclusive situation was what we were looking for and that's not offered…the public school doesn't have that, they just have the special ed preschool and we didn't want that environment, so it was a matter of which preschool to take him to and this was the one.

Hiedi shared that the EI service coordinator also prepared her for the transition. She described her role in the transition process:

> At some point in the infant program, I think probably when he turned two…we talked about [transition]…through the case manager. They kinda tell you that…you have a choice; to start with, at three years old you have to get booted out of the infant program. So they would give you something in writing…like where you went to the [special education department]…you have to go to get tested at the special education [department] and you have to have it done by a certain goal time if you wanted to enroll your child in the preschool.

Hiedi also described her feelings about the testing that had to be done prior to the transition: "That was a different OT [testing]…that's kind of a daunting thing a little bit…you want your child to do well and people you don't know are "evaling your child," but that's just something you have to do."

Hiedi felt that other parents of children with disabilities played a large part in preparing her for the transition. She shared those instances as well:

> You heard from other people with children a little older what they had gone through, from the other parents, so you're asking them as well, like "What did

> you do again?" and "When do you do this?"…Because I had friends who had gone here and I knew a little bit about the program, it was helpful. I already had heard…through a friend about this preschool, and then I started asking other Mom's…with kids with disabilities… "Where does your kid go?" "What do you think?" and so you start a while ahead of time.

Hiedi credited other parents for informing her about the inclusion program and indicated that she was thankful that she knew about it. She shared that although the EI service coordinator did mention inclusion, parents were not pushed in that direction. The emphasis was definitely on transitioning to the public ECSE program. It was up to her to find out more information about inclusion from other parents of children with disabilities; those who went before her:

> Trying to get parent's involvement or help was really nice, but if I hadn't known anybody, I would have been "up the creek." I would have probably just taken him to the regular [public school] because that's what they…tend to encourage you to go to the public school. And I talked to several parents since, they didn't know about [inclusion preschool] and so I'm feeling very thankful that I knew about it.

Hiedi had a difficult time recalling events surrounding the transition, particularly relating to the role of the occupational therapist. She did not remember the OT doing anything in preparing her for the transition although she did recall a "gap" in services. She related the gaps in services to schedules, vacations, hospitalizations, and other activities that impeded her ability to access the services of the occupational therapist in the EI program prior to the transition. When asked what the OT could have done differently to make her transition smoother, Hiedi replied that she would have liked more collaboration between the therapists in EI and inclusion preschool, such as ideas on things for the IEP and more specific recommendations. She would have liked details about his activities and treatment in writing. Hiedi also shared that she would have liked a parent mentor to help her through the transition: "It would be nice to have, like, a "parent mentor," so that would be ideal, I think, someone to say "hey, you know, my child just went through," and that might be something helpful for the infant program."

Importance, Role and Benefits of Occupational Therapy

Hiedi felt that occupational therapy in the EI program was very important for Michael. She reflected on his needs for OT and the role she perceived the OT serving for Michael in that program:

> It's important that he learns how to write…I mean he needs that…he needed [OT]. PT, he needs that to walk and such, but he also needs the OT, so it all works together to make him….He has very low muscle tone so she's trying to get him, his trunk, getting that stabilized and then from there you can go out…it was very important.

Hiedi identified the role that she felt occupational therapy played for Michael in the EI program:

> I think to help make the child help to gain skills and help develop those areas that are delayed so he can be more as "normal," quote unquote, "normal as possible." She would help me with feeding issues, and she was able to see how he was chewing and moving things back and forth…and to drink, some

> techniques with drinking, cause that's all new for me. [She would] bring…toys and things and would encourage us to do different exercises at home.

Occupational therapy in EI occurred in the family's home and Hiedi felt that it was beneficial for Michael because otherwise she would not know the problems to work on and what to do to help him. She described the benefits:

> For me…just to make sure I was doing the right thing…she was able to alleviate some fears as far as types of [food] textures to give him [and] knowing certain things I could do to help my son progress. If Michael is doing better, that makes us feel better that he's progressing as far as he can.

Hiedi elaborated on her perceptions of occupational therapy in the ECSE preschool program. She explained the contributions that the occupational therapist made, and the role that she served for Michael in that program:

> I think she's [OT] very important in his overall long term goals of him being…able to read and write and eat normally and gosh everything…I still think [OT is] of course, very important. She's working on like balance and trunk control and again that fine motor stuff. They try to do most of the things in the classroom as much as possible…I think he's in the classroom for the most part…or they might…take him out separately, and sometimes another child will come with them. It [OT] definitely needs to be, as much as possible, in the classroom so he's not missing out on…other activities. So that other children are also invited to join them in some of their activities so it's fun and it's not like, "Where did Michael go? Why is he being taken out of class?"…Cause you don't want to miss out on the class activities and to be seen as "different."

> There is a teacher coming in for him but, this is positive, I mean they have fun toys and our kids can play with those toys.

Differences between occupational therapy in the EI program and in the ECSE program were not as evident to Hiedi. She felt that not being able to observe therapy sessions in the ECSE inclusion preschool impeded her ability to determine differences between occupational therapy programs:

> Well, again, it's a little bit different, "different kettle of fish," you might say, or "apples and oranges," you can't compare exactly, cause again, I'm not watching the gal here [ECSE OT], so it's just kinda hard to say, but I think they're both very good occupational therapists…I feel they were tying to do the best for my son. We'd have team meetings once a month in the preschool program while in the infant program we would have like every six months…goals we were talking about. Also I was there in the OT [in EI] where the OT program was being administered and so I was able to talk with the OT there, so I don't know. I see them once a month [in ECSE], but I'm also not there to see what's physically going on…it's harder to comment on that cause I don't see it as much. We have monthly team meetings and there's a little progress report that they [we] talk about [in ECSE] and we verbally talk about things, but…I'm not visually seeing her activities. I don't see what's going on as much because it's done in the classroom so I don't see it up close as much.

Although Hiedi was unable to identify benefits of Michael's occupational therapy in ECSE preschool for her family, she was able to identify the benefits of occupational therapy in ECSE preschool for Michael:

> I feel like they're working together as a team really well here…and he's getting more frequent visits from people (i.e., therapists, teachers). He's also seated in the room with normal children four days a week and…he can also mimic that, so I'm seeing the outcome and I think the OT's a part of that.

Relationships, Feelings and Satisfaction

Hiedi described her relationship and feelings about the EI program in general. She felt that they made a concerted effort to meet the needs of the families however she was left feeling that more could have been done in the form of more frequent therapies:

> I think they did a good job, I felt they really tried to 'be there' for the parents and they would do extra curricular activities also which…was sometimes into evening hours and little parties and such. I think the biggest thing for me was I would have liked to [have] seen it (OT) more than once a week, even if the program was shorter, you know, like more frequently, like twice a week or something. I appreciated all that they did…cause they were trained to do these things to help us get to know other parents and make it a fun thing too, so I wasn't negating those, those are nice, but if you had a choice I'd rather have…another hour session a week…I think the child would benefit more from that and for me.

Hiedi explained further that she discussed this possibility of more frequent therapies with the occupational therapist that worked with Michael in EI:

> A half hour once a week doesn't seem to be very much; I would have liked it to [have] been more. We talked about that a little bit, but…it seemed like to

> be…all that they could provide, and I think she thought he was making…a sufficient progress perhaps.

Hiedi liked Michael's occupational therapist in the EI program; she described her feelings and their relationship as professional:

> I like who my OT was and thought she was very good…very professional. I think she was a very knowledgeable person…she did her job and she does a very good job…she's very good…A little more cooler personality, but that doesn't mean that her skill level is not adequate, that's just a personality thing. I felt like I got good care it's just a personality thing.

Hiedi was genuinely satisfied with the overall ECSE inclusion preschool program. She elaborated on the feelings she got from the people there and her feelings about that program:

> I love it, and it's really helped Michael so much, I feel protected and I know that he's loved. [The director], she really loves this little child of mine and I feel like the teachers are caring and his therapists are caring…and because he's here more days they [are] usually helpful for him.

Hiedi was very pleased with Michael's occupational therapy services in ECSE and liked that he received more therapy services in the inclusion preschool program: "I think it's so good for him, I'm seeing more changes in him." She also described her feelings and relationship with Michael's occupational therapist in the inclusion preschool program:

> I see her sometimes in the grocery store, I say hello to her, I know who she is. She's a really neat person; she's just a little bit more open and bubbly. I think I

> "click" a little bit more with this gal…it's more personality things versus a skill level…I feel like I can talk to her a little more easily just because she's a more bubbly personality.

When asked about her feelings about the amount of control of Michael's occupational therapy services, Hiedi replied that she felt that she had more control in the ECSE program than in the EI program. She credits the increased control to her ability to have more input with his therapists, particularly during their monthly meetings: "I think I might have a little more control…in the preschool…because I think the therapists might have a little more say on the needs of the child."

Contact and Communication

Contact and communication with Michael's occupational therapist in EI occurred at every session for Hiedi therefore communication was primarily verbal. Hiedi explained how the typical session went and the level of communication that occurred during the sessions:

> She would verbally say "work on having him pull…cheerios or crackers out of your hand, have him drink a certain way,"…She did give, verbally, instructions…she did explain it the first time. She had…her goals and those were talked about at different intervals…but I don't think it was like an everyday thing.

Hiedi also explained that updates on Michael's progress were explained to her verbally, such as, when the IFSP goals and objectives were reviewed: "She was in my home, so it was verbally. I was signing off …on a goal sheet, she had a goal sheet so I'd take a look at that." Hiedi also received some information in writing such as a copy of the IFSP or specific goals: "There may be a few times where she may have made a copy for me of the IFSP, of the goals that she had for him, there may have been a few times."

For Hiedi, communication was more effective when it was provided in writing. She explained what she felt would be the ideal form of communication with the occupational therapist in EI:

> I think I'm a visual learner, and I think seeing things in writing is helpful for me…not necessarily for the whole year…I need it broken down…the general goal…for this month. To have them spell out more exactly… "For this month we're gonna work on putting blocks in or stringing beads…and I'm gonna check on those next week," just encourage you. That would have been helpful for me, some specific short, like two or three things…to work on this week.

Hiedi also shared that she would have liked explanations of therapy explained more frequently, or perhaps with more repetition: "I think that [explanations of therapy] could have been explained maybe a little bit more, again, she may have said something like one time but…I need a little more repetition."

Hiedi was more satisfied with the level of communication that occurred with the occupational therapist in the ECSE program, primarily because team meetings were held on a monthly basis where she was able to meet with Michael's entire team:

> I guess I'm feeling fine with it…it's interesting because I'm not seeing her…"doing her thing," but I feel once a month is OK…I feel satisfied with it. We have a once a month team meeting where we discuss the progress and …each person from each discipline comes and has their input. I meet with the

> therapists in one group and his preschool teacher as well, and…the preschool administrator director…so it's everybody, a team meeting…it's nice to have all the disciplines there, they can talk to one another versus just "one person here, one person there."

Hiedi also requested from the occupational therapist that she receive monthly goals to work on at home: "Monthly goals that I requested…for at home and he has his IEP and once a month she [OT] communicates to me how he's doing in her area. I appreciate having something in writing…I need that."

Hiedi also explained that communication sometimes occurs through the preschool teacher in the ECSE inclusion preschool, but that everyone on the team had access to a notebook in Michael's backpack:

> The special ed teacher at the time said "Oh, [the OT] says to…for him to do this," so there was communication through the special ed teacher. [If] something unusual happens there's a notebook in his backpack if any of the disciplines want to write a note they can…but it's usually the special ed teacher that…would write the notes for the most part.

Family Involvement and Participation

Hiedi tried to involve herself in Michael's OT sessions as much as possible while in EI. She shared what she perceived as her role during his sessions in their home:

> I was trying to observe and see what they were doing so I could try to mimic it more; and asking questions. Sometimes I observed some things, and sometimes

> I helped as much as I…what I thought I could do. I guess I felt like "oh, I gotta learn this stuff," so I could try to remember it so I could help my child.

Hiedi also shared that sometimes her involvement in learning some of the techniques the OT taught her was stressful and led to feelings of guilt if the techniques were difficult for her or if she did not have the time in her day:

> It is [stressful] and then you feel guilty if you can't…like "oh my gosh how I'm gonna do this and gotta get all this other stuff in life done too." For me it's a balance and I'm…a little more comfortable with it now as we've progressed a few more years down the road. I have a life to live, Michael has a life to live, and we put these things in when we can, as much as we can, but…there is a guilt, I guess a little bit, like "Aaagh, I got to this done"! I guess we always feel that way though with our kids, our normal kids too!

Hiedi also explained that she was sometimes unsure about how to be involved in Michael's occupational therapy sessions while in EI and felt that the occupational therapist could have involved her more by asking her to do things with Michael during his sessions:

> Because I don't know what I'm doing, I'm not the professional…If I knew what I was doing…I guess she could say "Oh Hiedi, won't you try this," or there could have been more "OK Hiedi, I want you to try bouncing him on the ball and I'm gonna tell you how to do it"…as I'm thinking about that, that could have been done perhaps. I didn't think to ask it…so many things I didn't even think to ask.

Having the opportunity to "carry over" the work of the OT, or at least support it was important for Hiedi. She was left feeling inadequate in some ways because she did not have the level of guidance from the OT that she felt she needed to do this.

Hiedi was also involved to some extent in the development of Michael's IFSP in EI. She explained that the service coordinator derived the goals and provided her with a copy prior to the meeting to see if she wanted to add or change anything. Hiedi was comfortable adding or making changes to the IFSP and this was discussed at the meeting: "I was comfortable being able to tell the case manager person…we would meet together and if I wanted to add something, or we'd talk about it."

Hiedi felt involved in Michael's occupational therapy program in the ECSE inclusion preschool program as well. She shared that although she did not observe his sessions at school, she felt involved through the monthly team meetings and receiving monthly goals:

> I have the once a month input or the team meetings. I have input there…I'm involved in it. I like to have a monthly goal from each discipline, so the OT gave me a goal to do and again it has to do more with his fine motor…his hands and it's like to pull scarves out of a…diaper wipe box…to help to strengthen that…grasp. [If] there's some unique thing they would like me to [do], they will show me…they would show me how to do that.

Hiedi has never asked to observe occupational therapy sessions at the inclusion preschool, however she felt that the OT would be fine with her watching the sessions but maybe not actually doing things during the session.

Hiedi was also involved in the development of Michael's IEP in the ECSE program. She took the opportunity to give input to his IEP, but sometimes felt uncertain about the developmental levels that would come next:

> It's because what you know I don't know, developmentally, levels he should be at…they do give that outline you know of what are his weaknesses and strengths, and you can, based on that front report from the special education [department], you can say "OK, he's low on this what can we do to bump that up?" [I gave input], as much as I knew how, or like at our last meeting I said "well, he's not meeting his goals and…we're getting short of the end of [the] school year, what are we going to do about it?"

Summary

Hiedi's story revealed six categories. She was initially resistive toward the transition. The prospect of leaving the familiar and comfortable routine of the EI program was initially scary. Only by speaking to other parents of children with disabilities who had previously made the transition to ECSE did she find the comfort and trust that alleviated her fears and feelings about impending transition. Hiedi and her husband took full advantage of the programs available that provided information about the transition. They attended various workshops and meetings; however, what really helped the most was the parent network that Hiedi came to rely on. It was the informal network of friends and other parents of children with disabilities that were able to provide her the information she needed about inclusion preschools in her area; an option not previously provided to her by the EI program. This informal parent network held the key for her preparation for transition. Hiedi felt that occupational therapy was important for Michael in both the EI and the ECSE programs. She viewed OT in EI as helping Michael gain skills in developmental areas but also helping her to alleviate fears and to help her son progress. In contrast, she viewed OT in ECSE as primarily helping Michael in developmental areas necessary to participate in his classroom environment. Although Hiedi does not often have the opportunity to observe OT in ECSE, she is confident that services are sufficient to meet his needs; a confidence she gets from communicating and interacting with his therapists during monthly meetings, thus highlighting the importance, role and benefits of occupational therapy. Hiedi described a professional relationship with Michael's OT in EI. She felt he would benefit from more OT and discussed that possibility with his OT. Hiedi would have like more from her EI program. In ECSE, Michael did receive more OT services, which pleased Hiedi immensely. She felt that his services in ECSE were meeting his needs and felt a genuine sense of caring as well as control in that program; a sense she got from talking more openly with his OT in ECSE. This is reflected in relationships, feelings and satisfaction. Hiedi discussed her preference for written instructions and goals to work on at home. This would have helped her to feel more connected to the therapeutic process in EI. She elaborated on the level and means of communication with the occupational therapist in both the EI and ECSE programs in contact and communication. Hiedi shared her uncertainty of how to help in occupational therapy while Michael was in the EI program and her feelings of stress and uncertainty surrounding her involvement. Additionally, she discussed how she was involved in the development of the IFSP as well as the IEP in the respective programs and her comfort level in having input to the IFSP. She felt like she was in an unfamiliar world and the professionals who were there to help her sometimes went about their business of helping Michael without always helping her to feel involved in that process in family involvement and participation.

Katie and Melanie

Background Information

Katie was a mother of a five-year-old girl, Melanie, who was diagnosed with having myotonic dystrophy and was her only child. Katie described Melanie's need for occupational therapy services because of low muscle tone in her trunk and upper body. Katie was interviewed at her daughter's preschool located in a local church. The interview was conducted in a small room off of the main corridor of the sanctuary that was generally used for Bible study classes. The interview lasted approximately 45 minutes and was audiotaped. In addition, a three-minute follow up interview was conducted over the telephone and also audiotaped. Melanie's preschool participated in an inclusion program for youngsters with developmental delays in cooperation with the local school division. The local school division supported the inclusion preschool program by providing supportive services at the preschool site, such as occupational, physical, and speech therapies as well as a special education teacher that served as consultant.

Melanie was five years old at the time of this interview and was eligible to receive special education services with a classification of developmental delay. At the time of this interview, Melanie was finishing up her second year in this ECSE inclusion preschool program. As part of her ECSE program in the inclusion preschool, she received occupational therapy twice weekly for thirty minute sessions, physical therapy once a week for thirty minutes, and speech therapy three times a week for thirty minutes each session. A special education teacher also visited Melanie in her class twice a week and visited the family at home once per month.

Prior to enrollment in the public ECSE preschool program, Melanie received EI services in their county. In this program she participated in occupational therapy, physical therapy and speech therapy services, however therapies were provided at a center and a teacher visited the family in their home once or twice a month. Katie explained how she brought her to the center on certain days to participate in therapies as well as group time:

> We went and we had a little classroom time where you sit around with other mothers that are there and you played little games and then the child actually would come in on a separate day to get their therapy.

Melanie then transitioned to the public ECSE preschool program at the age of two. She attended the public ECSE preschool three days a week and was also enrolled in a private preschool for “social interaction" two days a week. Melanie received her therapies (e.g., OT, PT, speech) as part of her preschool day in the public ECSE preschool program. Since Melanie initially entered the public ECSE preschool following the transition from EI, she rode the bus to the local elementary school where her ECSE classroom was located to receive her therapies. Katie explained how therapies were provided in the classroom there:

> When she went to [public ECSE] preschool…that’s where she got all the therapists [coming] into the classroom and working with the children. …They did a whole class group, the whole class participated and they had a speech

> center, a PT center, another craft center, so the child in groups of four would rotate around and all the children really benefited from that.

A distinction will be made throughout to distinguish the public ECSE preschool program from that of the ECSE inclusion preschool. During Melanie's placement in the public ECSE preschool, Katie became increasingly concerned with Melanie's mimicking inappropriate negative behaviors of other children in her preschool class and wanted more appropriate role models for both behavior and academics. It was during this first year in the public ECSE preschool that Katie decided to pursue placement for Melanie in the inclusion preschool program. Katie also explained that after moving to the inclusion ECSE preschool program, Melanie began receiving her therapies out of the classroom, in a separate room away from the other children in the class. Katie brought Melanie to preschool early on those days so that she can get her therapies before her preschool class started.

At the time of this interview, Katie and Melanie were preparing for a transition, to Kindergarten in the public schools. Katie shared that she is concerned about the effectiveness of the transition, from both a social and academic standpoint as well as Melanie's comfort level with her new environment: "…that's my big concern now as she transfers to Kindergarten, how effective is the transition going to be…you really have to just stay on top of things."

Fears and Feelings About Impending Transition

Prior to Melanie's transition from EI to ECSE, Katie shared that she didn't feel ready for the transition and was nervous about entering the public school system. Katie was concerned about the transition to the public school system and particularly with

Melanie’s services such as occupational and physical therapy and the ability of the two programs to communicate effectively in the transition:

> [I was concerned] that they would be able to communicate effectively, be able to pick her up and know what works and what doesn’t work…you always hear that when you transition into a preschool program at the public school system that…they don’t have the staff to give your child the services that you may feel that the child needs, they’re going to try to drop your services. I think that’s a concern of most parents. Not drop services altogether, but cut down on services.

Preparation for Transition

Following the decision to transition Melanie to the public ECSE preschool program at the age of two, Katie began transition activities. She explained that the teacher in the early EI program did most of the preparation for her and gave her the information she needed. She also shared that other parents served as a source of support and information for her: “…I tried early on to get “plugged into” support groups of parents and I think that…you learn from what other peoples’ experiences have been and that’s how I learned about [the transition].”

Katie recounted the activities that she engaged in prior to the transition, including exiting the EI program and attending an informative meeting by the school system and how these activities were comforting for her:

> [I] think that her [EI] teacher did come out…before school actually started and …had maybe the IFSP and I probably signed off on it…[for school] I had to fill out, go in and do a registration form. They did have a special ed teacher in the

> public system come and speak…you could come and hear her view on how the transition happened and what to expect, so I know that they were trying to do that every year, that way the parents had a opportunity to ask any questions. They're very "in tuned" and…try to soothe and ease your mind that everything's gonna be fine…we talked about it in a group and tried to comfort you.

Katie also visited the public ECSE preschool classroom prior to the transition:

> I think I might have visited [the classroom] because I was concerned about if the children were going to be…particularly handicapped or very mentally handicapped. I was concerned about the population in that particular class so I did…go and observe that class because I knew that [inclusion program] was always an option.

Katie also described the role of the occupational therapist in the preparation for the transition. She was unsure of what the occupational therapist actually did for her in preparation either from the early intervention program or from the early childhood special education program. She was left feeling unsure that information important to Melanie's services was shared among the programs:

> I don't think I received anything from any therapist about what's going to happen…I think what [therapists] say is that they'll contact that, that OT directly, to update on what they're doing with that particular child in addition to the IFSP goals…for some reason I don't think that ever happened…I don't know that that didn't happen…I think she said she was going to call and whether that call actually took place, I'm not real sure, I think it probably did at some point, but after school gets started maybe.

Katie also described what she felt would be an ideal role of the occupational therapist in preparing her family for the transition:

> They probably could…just type up a sheet with what services Melanie's received, what progress she's made and how she responds to therapy…even giving it to the parent…it gives the parent some comfort that communication is actually happening [between EI and ECSE therapists].

Importance, Role and Benefits of Occupational Therapy

Katie described the occupational therapy services both she and Melanie received in the EI program and the role the occupational therapist played in that program:

> I think it's [OT] very important…I brought my daughter in [to the center]…she worked with her, and gave a list of things I could be doing at home. I think they did a lot of sensory things with her…getting balls out of sand, that type of stuff. They did a lot of ball work, trying to put things on or in things, that type of stuff.

Katie viewed occupational therapy services in EI as parental training as well as developmental therapy for her daughter's difficulties. She also viewed occupational therapy as beneficial to Melanie's EI program: "I think it's a very beneficial service, I think I had a clear understanding from the OT with what OT did, I mean before that you don't know what OT does."

Katie also described her view of the role of the occupational therapist in Melanie's ECSE preschool program:

> They work on a lot of strengthening activities…she does a lot of weight bearing activities…and then she also works on writing, a lot of prewriting strokes and mazes. They also do a lot of cutting with her…they work on cutting different

> patterns and things like that…specific skills that she is expected to do in Kindergarten. She's [OT] supporting all of her goals…she's supporting those goals in the IEP, I think in the classroom and working on specific things.

Katie explained how she viewed occupational therapy in the preschool program as parental training as well: "I think it's important to carry through at home and practice because that's not gonna get those skills better. I look at it [OT] more as a…parental training as opposed to fix[ing] my daughter."

Katie was also able to identify benefits of occupational therapy services in Melanie's ECSE preschool program to both Melanie as well as her family: "It makes me feel better…just the communication in knowing kind of where we're at with her and what areas we work on."

Relationships, Feelings and Satisfaction

Katie shared that she was satisfied with the occupational therapy that Melanie received in the EI program and that it met her needs. That was the first time Katie was involved with occupational therapy and some aspects of it were overwhelming to her:

> I think when you go into the early intervention program you're probably in shock for the first two years that your child's even involved in the therapy, so they're…just kind, you're gathering with mothers who all "have this" [child with a disability]. [You're in] the same boat, they didn't expect to ever be there and this is the first child they've had with special needs and you're just in shock. I think when your child's younger, when you first get involved in early intervention, I think you can get overwhelmed with [it] all…it's new to

> you…you don't understand the therapies and all this stuff that they do…it was kind of overwhelming.

Katie did gain a sense of comfort from the EI program and the therapists: "It's more of a comforting environment…the therapists are very in tune with the parents and things like that…it was great."

Katie also described her relationship with the occupational therapist in the EI program. Melanie had the same occupational therapist for most of her time in EI, however near the time of the transition her occupational therapist left to take a new position elsewhere. Katie described her relationship with the OT and how she felt when the therapist left:

> I really liked her a lot, I would say it was probably more of a professional relationship but you know at the same time…a "part friendship." I was disappointed to see her go because she worked so well with my daughter.

Following the transition to the public ECSE preschool program, Katie was not as satisfied with the occupational therapist in that program. She spoke with the OT there who then provided individual therapy sessions for Melanie as Katie requested:

> When she …graduated from the early intervention program she went to the public preschool, and I just wasn't that satisfied with the therapist that saw her there. We did that a couple of months, and then I felt my daughter needed more one to one instruction, so I came to the [OT] and I said I really think that she needs more one to one to work on specific [skills]…and she said "no problem."

Katie ultimately made the decision to enroll Melanie in the ECSE inclusion preschool program, necessitating a change in therapists at that time. She described her feelings about occupational therapy in the new inclusion preschool program:

> I love OT. I think a lot of [my satisfaction] has to do with the " teacher" [referring to the OT] though. The therapist now is very aggressive; just uses that entire time one hundred percent of the time and just does a lot with the child during that session. That's why I think I'm so happy with it and we've seen great improvement over the past couple of years with OT…

Katie also formed a relationship with the occupational therapist in the ECSE inclusion preschool program. She described her relationship with Melanie's occupational therapist: "It's wonderful because I'm happy with what she's doing with my daughter; when I see her sessions she's using that entire time effectively."

Family Involvement and Participation

Katie was very involved in Melanie's occupational therapy program in EI and felt like she was as involved as she wanted to be. She described her typical involvement: "The parent typically would stay with the teacher [OT] during that time because the child's [very young]." Katie was not very involved with the development of Melanie's IFSP in EI and she explored why this may have been the case: "I probably didn't know enough to add [objectives to the IFSP], I mean it seemed satisfactory at the time."

Following the transition from EI, Katie was also involved in occupational therapy sessions in the public ECSE preschool by observing on the days that occupational therapy occurred. Her involvement led her to realize that Melanie's needs were not being met using the integrated therapy model in the classroom:

> That gave me the opportunity to really see what was going on. That's what made me make the decision that she's got four other kids to work with, it would be nice if Melanie could just have the one to one time…and that's worked out very well.

In the ECSE inclusion preschool program, Katie's involvement increased as she observed each session and took notes to follow up on at home. She recognized that Melanie's occupational therapy program in the ECSE inclusion preschool was very helpful, however, she also realized that it could not meet all of her needs. Katie also recognized that it was equally important for her to observe OT sessions so that she could follow-through with techniques at home:

> I don't believe that occupational therapy twice a week for thirty minutes is going to give my daughter all she needs. I attend her sessions once a week. That way it gives me…lets me know very clearly what areas I need to be following through at home. I'm the kind of parent that wants to know exactly what they're doing, so I implement that at home. I became a lot more involved when she transferred to this program.

Katie was also involved with the IEP development in ECSE. She described this process and her involvement in the IEP at the time of the meeting:

> They're very open towards [my involvement]. They have a draft copy, but they're very flexible about me adding things to the list that are realistic that she

> can achieve. When we determine goals for Melanie, I'm involved in adding goals…to that section.

Katie felt very strongly that her involvement was beneficial to Melanie's ECSE inclusion preschool experience. She described the benefits of her involvement in Melanie's occupational therapy at school:

> I'm on the other side of the room and just can verbally hear and see what specifically she's working on. That gives me a lot of peace of mind and comfort and being able to see her progress, see what she's able to do as opposed to the beginning of the year.

Katie also described a potential barrier to her involvement in Melanie's occupational therapy at school. She implied that occasionally Melanie's behaviors interfere with her involvement: "If my daughter starts acting up I leave the room." She also recognized that here were differences in her role and involvement changed when the transition from EI to ECSE occurred: "[In] the early intervention you're helping the child…and you're right there, working directly with the child. It's more observing [in ECSE] when the child gets older to see how they work with the therapist."

Contact and Communication

Communication in the EI program was primarily verbal with the teachers and therapists, however the IFSP was reviewed with Katie on a regular basis. She described how this occurred: "She'd [EI teacher] bring that [IFSP] to my house when she came for home visits and we'd go over the progress…once a quarter…whenever that was required…the teacher went over that with me." Communication with the occupational therapist in EI was also primarily verbal since Katie was involved and participated in all of the sessions. Katie described that she received written activities from the OT in EI to work on at home with Melanie. Katie was satisfied with that level of communication and felt that the OT extended herself to her by giving her her home phone number if she had any questions.

Katie described the level of communication with the occupational therapist in the public ECSE preschool program prior to Melanie's move to the ECSE inclusion preschool in contrast to her EI experience, as very indirect.:

> My only point of communication with those people [the therapists] were they said you can call them and "all that stuff," but my only point of communication was through the teacher as to what was going on at our team meetings twice a month.

Katie also described the level of communication in the ECSE inclusion preschool program. She shared that in preschool they had regular team meetings once a month that included her as well as the classroom and the special education teachers, the occupational, physical and speech therapists, and the school director. At the team meetings progress was discussed and work samples were shared as well:

> By having the team meetings everybody knows "what page we're on," even her regular ed teacher, and the director of the school comes, too, so we all kind of know what we're focusing in on. Everybody sat down and said: "This is what Melanie…This is what I'm working on…This is the main focus" You have the team meeting with all the therapists [and] everybody just kind of knows what the main issues are…it's just nice to have a consensus. …You can identify the

> area…which was more important to work on and it just became more apparent when all the therapists got together.

Katie was satisfied with her level of communication with the occupational therapist in the ECSE inclusion preschool. She shared that although the communication was primarily verbal, she preferred that over the therapist having to spend Melanie's therapy time writing her a note: "She's so busy working with the child, she would rather do therapy the whole time than spend five minutes writing in the notebook what they did today and I'm one hundred percent fine with that."

The communication with the occupational therapist in the inclusion preschool program was primarily verbal, during treatment sessions that Katie observed. Communication also occurred via written activities and books that were given to her. Katie was also able to use notes and ideas that she jotted down at the team meetings to help Melanie at home in addition to the activities and books that were provided.

Katie was able to identify the benefits of the communication that she enjoyed in the ECSE preschool inclusion program: "It…just verifies what track we're on and what page we're all on and what's the most important goal to work on for my daughter." She also shared an example that exemplified the benefits of regular communication with the occupational therapist:

> My daughter's got visual perceptual problems…she's got to have a model…some kind of visual tactile cue, well I didn't know that…I was just trying to get her to practice letters for a couple of months…she [OT] said, "Katie, you're beating your head up against a wall, you've got to start out [with a certain method], that's the way she's gonna have to learn it," so that was a

> great benefit, that communication, cause otherwise I could have been beating myself up against a wall forever without that communication.

Summary

Six categories were identified in Katie's story. Katie shared that she didn't feel ready for the transition and that she was concerned about effective communication in the new preschool. She was also concerned that Melanie's services might be reduced once they transitioned in fears and feelings of impending transition. She shared her uncertainty and disappointment that information was not shared between the occupational therapists in the two systems, information that she felt was important to Melanie's successful transition. Katie lamented on the importance of her support system, other parents of children with disabilities, in giving her the information she needed in preparation for transition. Katie described the OT's both in EI and in ECSE as working on necessary developmental skills for Melanie, but also providing parental training for her to follow-through at home, something Katie believes in very strongly in importance, role and benefits of occupational therapy. Katie had a sense of friendship with the OT in EI, something she missed after Melanie transitioned to ECSE. She felt a sense of comfort from the EI OT that helped her to deal with and accept the shock of having a child with a disability. Following the transition, Katie was not as satisfied with Melanie's OT services in the public ECSE program, prompting her to request individual sessions and eventually move Melanie to an inclusive preschool environment in relationships, feelings and satisfaction. Katie's participation in OT changed after Melanie transitioned. In EI, she was part of the therapy process, participated in all the sessions and learned from the experience. In ECSE, although Katie continues to learn from the experience, she has taken a back seat to the therapist and prefers to observe the sessions rather that actively participate. She described this change in participation in family involvement and participation. Communication with the occupational therapist has been very different for Katie between the three programs she has been involved in. In EI, her communication was verbal and Katie was satisfied with this informality of talking to a therapist that she also considered a friend. Following the transition to ECSE public preschool, communication with the OT was inconsistent and very indirect, with most information coming through the classroom teacher. Katie again found satisfaction in the level of information she received once Melanie moved to the inclusion preschool. There she is able to gain information and communicate with Melanie's therapists through informal meeting, observing treatment sessions, and through monthly team meetings, giving her a sense of connectedness and control of Melanie's services in contact and communication.

Kathy and Adam

Background Information

Kathy was the mother of two sons ages 16 and 5. She is married, and her youngest son, Adam, has Down syndrome. They lived in a duplex home on a military housing complex in southeastern Virginia. Debbie was interviewed in the living room of her home while her children were at school and her husband was at work. The interview lasted approximately 60 minutes and was audiotaped. An additional follow-up interview was conducted that lasted four minutes and was also audiotaped.

Adam attended the local elementary school in an ECSE preschool class, which was a half-day program. Adam went to school in the afternoon (i.e., p.m. session). At the time of the interview he had been attending a new preschool for approximately five months. As part of his ECSE program in the public preschool, Adam received occupational therapy services twice per week for twenty-minute sessions. In addition, he also received physical therapy and speech therapy services. A special education teacher also visited their home once during each month. Adam qualified for special education services due to his medical diagnosis of Down syndrome and the developmental delays associated with it. His special education category was developmentally delayed.

Prior to Adam's enrollment in the public ECSE preschool program, Adam was enrolled in an ECSE inclusion preschool program housed in a local church, which was supported by the local school division. He transitioned to this program from EI when he was two and a half years old. The local school division provided supportive therapies as part of the ECSE inclusion preschool program such as occupational therapy, physical therapy and speech therapy. In addition, a special education teacher, who also made regular visits to the family's home, worked with him in his classroom. These supportive services were included in his IEP. Services were provided in a private preschool environment with age appropriate, normally developing peers. Adam was enrolled in this program for over two years prior to his move to the public ECSE preschool program. A distinction will be made throughout this report to distinguish public ECSE preschool from ECSE inclusion preschool as Adam attended both throughout his ECSE experience.

The family initially transitioned from EI when Adam was two and a half years old. Prior to receiving inclusion preschool services, Adam received services through the

EI program in their county. He started this program when he was approximately seven to nine months old. In this program, he received occupational therapy services and he went to an intervention (i.e., group) class at the early intervention center. All of Adam's EI services occurred at the early intervention center because Kathy preferred it that way. Adam's occupational therapy services occurred once per week and lasted approximately forty-five minutes.

Fears and Feelings About Impending Transition

Initially, Kathy really had no fears or concerns about the impending transition from EI to ECSE; in fact, she was excited that Adam would have the chance to go to school with his peers in an inclusion program:

> I don't really think I had any concerns. I think that we were so happy that we were going to be able to try to include him in the regular preschool setting and that we knew that our team, the special ed team that was coming in, was supposed to be really good, so we knew that. [We knew] that there would be an adjustment period, but…they were going to help ease him into it…the people at the school had already gone through that so they knew what to expect and what to do."

After giving it some additional thought, Kathy recognized that she did have some initial fears and concerns surrounding the transition. She worried about whether Adam was emotionally ready for the transition and it felt like a "big step" for them both to make.

> Here you are, not knowing what to expect anyway…out of your child, and then you've got these group of people telling you "oh he's going to do wonderful

> things, this, this and this," you're not sure you want to [transition]…it's like sending your kid off to college…is he ready for the next step? [It felt like] I was sending him to big boy school and oh my gosh he's so little.

Kathy was also concerned about Adam's developmental level and wasn't sure he was emotionally ready:

> He was two and a half and he went into a preschool setting that the kids were…two and a half but you knew that developmentally he wasn't two and a half and emotionally he wasn't two and a half, so…it was hard. I didn't feel like he was ready to make that next move.

Further reflection revealed that the need for Adam to ride the bus to school was also a concern for Kathy. She knew that Adam liked to watch buses go around, but she wasn't so sure he would like to ride one because big things normally scared Adam. He was scared the first couple of days, but then "you couldn't get him off the bus." Kathy was relieved that this concern was resolved relatively quickly.

Kathy expressed similar concerns about Adam's upcoming transition to Kindergarten:

> I'm hesitant. It's coming up real soon and…you're constantly struggling with what you think your child can do and what they're [the educational and related services staff] not going to do for your child and …what's best and "who do you listen to?"

Preparation for Transition

When the time came for Adam to transition to ECSE, the EI service coordinator helped Kathy and her family with the initial activities for the transition, but following those initial activities, Kathy felt abandoned and set out on “the journey alone.”

> The coordinator took care of…giving us the direction in which to go. She…helped us set up our appointments to go get evaluated for the preschool program and stuff like that. It was over the summer, we did all our testing and all the evals and stuff like that. But after that we were pretty much on our own.

Her friends and other parents of children with disabilities who had previously gone through the transition also prepared Kathy for the transition. Kathy shared her view of the role that her friends played in the transition; friends who knew the path in the journey of transition:

> I already knew what to expect from parents that had their children in [the inclusion program]. I have a good networking of friends that have kids with disabilities. They told me what to expect, how much I should expect, what to make sure that I should get…ask for certain things, they pretty much told me who the therapists would be. [I] heard wonderful things about the occupational therapist, so she had a good reputation and that was one of the reasons why we chose to go to that school was because of the therapists that were gonna be there.

Kathy also felt that the ECSE staff in the inclusion preschool helped her through the transition by providing her reassurance: “They were all very good, I don’t think it was anyone specifically. They were very reassuring that he was doing good and this and that…they just really made their best effort.”

Kathy didn't feel like the occupational therapists in the EI program played a substantial role in the transition: "By then [his regular OT] was gone and I was seen by the young girl when he was exiting, so…she didn't, they really didn't help the transition from intervention to [inclusion program]." An occupational therapist from the ECSE program did evaluate Adam prior to the transition, however Kathy had mixed feelings about her involvement: "We saw that group of therapists at the testing site…but they only saw him the once or the twice…so they're evaluating somebody they didn't really know."

In retrospect, Kathy was able to reflect on aspects of the transition and her feelings about the preparation:

> I think a lot of times as parents you assume that since it was that way at another place, it's gonna be that way at this place. I'm not so sure it's just the one-person thing to help the transition, I think it's a collaborative effort on a lot of people's part because there are a lot of questions that parents have and a lot of rights that parents don't know that they have. It's a difficult transition to go from one thing to the next thing, just like now going to the Kindergarten thing…you're going to different levels. So, I think the transition from [EI to inclusion preschool] went real well; the transition from [inclusion preschool] to public school has been a little bit different because you don't have as much communication with the other therapists.

Kathy felt that the transition could have been made more smooth and seamless by knowing in advance what Adam would be doing at the "next level." She really would have liked to know the people who were going to be working with Adam:

"[Knowing] who they're gonna have, because that's a big question…who's gonna be servicing this child?"

Importance, Role and Benefits of Occupational Therapy

Adam's occupational therapy services in EI were provided at the early intervention center, however Kathy remained present during his sessions. She recalled benefits of occupational therapy in EI as well as the role of the OT in that program:

> She [OT] was very beneficial at that point in my life…especially when you're just a new parent to something like that [disabilities]. [She was beneficial to my family] because…she showed us things that we could be doing at home to help Adam along and I think if someone hadn't have taken that approach with us, that it would keep Adam further behind. …As parents and you have a child with a disability, there is no guidebook, there is no one there to help you along, so you are counting on a lot of professionals to turn you in the right direction.

Kathy felt the only benefit that she received from EI was Adam's therapy services such as OT and PT. She felt that OT in ECSE was equally important in Adam's ECSE inclusion preschool:

It's very important [in ECSE] because a lot of kids have fine motor issues and sensory issues and I think that if you catch it early on it can make a big improvement later on as they're progressing. Holding the pencil and doing all these little things that they're gonna need…so I think it's very important.

Additionally, Kathy shared her view of the role that occupational therapy served in Adam's ECSE inclusion preschool:

> She would come in and work on goals that was on Adam's IEP that the teacher was also working on at the same time, so she would…come in and work on them goals…in a group and privately with him. She was there to lend support to the teacher…that's what I understood. She was willing to do just about anything to get Adam to focus and she was always so upbeat…she always came in with a smile and she was looking through all her books and going through all this data…to find ways that she could get Adam to do what it said on his IEP. She was always concerned about what's a better way to do this.

Kathy was able to distinguish the services that the Occupational therapists provided from those that the teacher provided in ECSE:

> The OT and the speech therapist…they have just a tad bit more knowledge than the teacher does on what may benefit Adam. I think they in turn give that information to the teacher so that when they're not there she can work on that. They do have a little bit more expertise at what they're doing and they can help, I think, they can help guide the teacher, too.

Kathy did not want to negate the role of Adam's classroom teacher: "She does everything. I couldn't say nothing negative about his school teacher…she does everything, so when the therapists aren't there, she fills in…she's just great."

Benefits of occupational therapy in Adam's public ECSE preschool were initially difficult for Kathy to determine because she no longer saw the occupational therapist:

> I really couldn't say because I'm not in there…[it] is beneficial that he does have it. It would hold him back…if he didn't have extra help with OT…he couldn't make it through some of the functions of the day.

Kathy was also unable to determine benefits of occupational therapy in public ECSE to her family.

Kathy did not feel like there were a lot of differences between Adam's occupational therapy services in EI and those in ECSE. She identified a difference in level of participation, communication, and one on one therapy versus group therapy:

> I'm not sure if the role is a whole lot different because…I think they both have Adam's best interest at heart. So, I think it's the fact that you really can't participate as much. I think [comparing] early intervention to [inclusion preschool] it was about the same because I had so much…communication with her [OT]. So, I think that's…the only thing that's different between the two, the communication and maybe the ability to participate. I think the quality is different, because if you're getting one on one it's the attention is all directed toward that one person. I don't think it's the same because it's one on one when he went to [early] intervention, and a lot of times in the school setting a lot of times its group.

Ideally, Kathy felt that for Adam to have more time with the occupational therapist in the public ECSE preschool program would be beneficial for him and that more communication or interaction with the therapist would be beneficial to the family:

> I think maybe a little bit more time spent with that child would be more beneficial because not all kids are gonna sit there and do what they're asked and

> be cooperative all the time…to see a little bit more service time. Maybe a little bit more interaction with the family would be benefiting us, but we don't get that.

Logistics of Occupational Therapy

Adam received his occupational therapy in the EI program at the early intervention center. Kathy explained that she was given a choice in where his services would occur:

> I could have gotten them in my home but I chose to go to the center because they had all the equipment and everything that they needed, and I felt like that he needed to get the best and the most out of his sessions that he could have. And they had everything that they need right there…so I felt that was a better environment for him to go to because they had everything at their disposal.

Also, therapy services in EI were scheduled at a convenient time for Kathy: "They slotted me for a time I asked for, so it was more convenient for me because I had other places that he had to go, so…that worked out well."

In the public ECSE preschool, therapy times were not as consistent, but that was not as concerning for Kathy:

> I know what day's most of the time that they [therapists] come. I'm not sure of the times and I think the times sometimes change because of…if they got other kids and stuff like that and that really doesn't concern me as long as I know Adam is getting what he's supposed to be getting.

Because Adam goes to the afternoon preschool session in the public ECSE preschool program, Kathy adjusts their other appointments around his school schedule:

> He goes to school in the afternoon, so I schedule everything else during the morning so it doesn't interfere with what he's doing at school, so scheduling at school was really not a big deal…if he wasn't getting the services then it would be a big deal.

Adam's occupational therapy is delivered in the classroom most of the time in the public ECSE preschool. Kathy explained how this is typically done and how the delivery of services is determined:

> It's pulled out to the side in the classroom, I'm pretty sure, and sometimes it can be individual. Everybody was in there…and they were taking the kids and pulling them one to one…and then they put the kids together. And it all depends on how, what the therapist thinks the child needs, if they feel they can do the one on one and do better at it, they will pull out sometimes, one on one, but if they think they do better in a group then it's always gonna be in a group setting.

Relationships, Feelings and Satisfaction

Kathy felt that she had good people to work with in EI and was very satisfied with the occupational therapy services that they received, however she did not feel like she really gained much from the experience: "We were done [with early intervention]…I didn't really gain a whole lot except for the OT through the infant program. I don't feel like it was 'that great' of an experience." Kathy felt that she was "lucky" to have such good people to work with, however. Adam had several occupational therapists in EI, and Kathy reflected on her relationship with each of them:

> I really liked the first therapist…she just kept me informed and on top of everything. She was also a friend…someone that you could talk to, so it was

> very nice that we sort of had like a friendship going at the same time she was treating Adam. She was very beneficial to me at that time. The woman was wonderful…she was just very helpful.

Following the first therapist, who worked with Adam for about a year, Kathy was "handed" two other OT's that she did not feel she "meshed" well with:

> [The next OT] she didn't stay long; she wasn't too bad. The next lady [last OT] was young…she was very new to doing OT and she wasn't very self confident. Adam can be very stubborn, by the time she was seeing Adam he was eighteen months old…he didn't want to do a lot of things that she required…it was a struggle between her and Adam, so then it became a struggle with all three of us because I didn't feel as if he was getting a whole lot out of it because she kept pushing the issue to make sure he did the one thing, the one thing, instead of trying a different approach or going to something totally different and working on that. I don't think that was a bad thing…I think it was just a lack of experience that she wasn't around a while and had a lot of experience on what to do and stuff. I hear she's doing really well now, now that she's been doing it for a while, but I think because of her lack of experience, but everybody has to start somewhere…it just didn't work out with us.

Kathy was very satisfied with the occupational therapy services that Adam received in the ECSE inclusion preschool as well. She described her feelings about the first occupational therapist Adam had since leaving the EI program:

> She [OT] was very good. [She] really went above and beyond and she was very talkative…and genuinely cared. I think they all did, some more than others,

> they took their work very seriously and it wasn't just work to them, it was personal. I know the speech and the OT were like that, they cared very much for what they were doing.

Kathy also reflected on her general feelings about the ECSE program in the public school and some of the people he's worked with in that program:

> Now that he's in public school he's doing much better than when he was in [inclusion preschool] so there are a lot more improvements since he's been in the preschool setting at school because I think they focus more on what he needs at school than what happened in [inclusion]. Putting him in public school has made a difference, a smaller classroom, [and] the more experienced teacher. They work real close together, they work in conjunction with each other, it's like a big team. They've really just tried to do everything that they could for Adam, so I can't say it's been a bad experience in the preschool setting for him. [The] preschool has been really good, except for the [inclusion preschool] experience, the public school I've really enjoyed being with them…he's really done well.

She also shared her general impression about the occupational therapy services in the public ECSE preschool program:

> I think to a certain extent it's [OT] good at school, but I think that because the therapists are only there part time and then only see him…twice a week for OT and the time's so limited you know. I can see some progress, but…I like to know who's working with my kid and what kind of personality they have and if

> "they're clicking" because if they're not clicking it's not going to be ideal for anybody to learn.

Because at the time of the interview, Adam had just recently moved to the public ECSE preschool program, he and Kathy were just starting to build a relationship with his occupational therapist and teacher. Kathy felt that the relationship was just starting to form: "He's just getting to know some of these people and getting used to them…they're trying to build up a rapport. Because when he first started seeing them…they, he really had a hard time, he's not good with change."

Kathy felt that her relationship with the therapists in the public ECSE program is different from that in EI "because you don't know them as well, you really don't." She described her relationship with his occupational therapist in the public ECSE preschool:

> I think we're friendly, and I probably could approach her and ask her to call me or to let me know what he's doing, but since we've been there such a short time, it was more of letting her get to know Adam and Adam getting to know her. I think you have a really close bond with some of these teachers [therapists] and especially his special ed teacher.

Kathy also reflected on her feeling about all of Adam's therapists over the last few years and has formed some general feelings about the therapeutic relationship:

> We've gone through lots of OT's and speech people…in five years, and some are better than others at it and I think it's the way that the OT, Speech, and PT people approach you and how comfortable they make you feel and how much the little extra they're willing to go to help benefit your family.

Kathy shared that she didn't feel a sense of control of Adam's services in the EI program. Unlike in EI, Kathy felt that she had more control of Adam's services in the public ECSE preschool program:

> I can pretty much go in there and ask or demand for certain goals that I think he needs to have and they usually are pretty good about letting me have it. So…we worked real well together last year in the preschool so he got pretty much what he needed.

Contact and Communication

Kathy felt that communication with the occupational therapist in the EI program was more frequent than in the ECSE. She communicated with the occupational therapist at every visit. Communication was primarily verbal and she described the typical weekly scenario:

> We talked every week and she would tell me what progress that she thought he was making so I knew…if he wasn't making any progress she would say, "Adam…you need to do this for your mommy!" The communication is different because when you're there with them doing it you're communicating all the time and you're talking and they're telling you ideas and things that…might benefit not just Adam but the whole family.

Kathy also liked that she was able to exchange things such as equipment or ideas with the occupational therapist in the EI program. She felt that she was a part of the therapy process:

> There were a lot of times that she would send specialized things home to do with Adam, "take this home and use this with him for a week and bring it back next

> week" or she would get me handouts like on feeding and brushing…sending me little things to help the process in any way that she could.

Communication with the occupational therapist in the ECSE inclusion preschool was different, but because of the timing of when the therapist worked with Adam, it was easy and convenient for Kathy to talk to her when she picked Adam up from school. Kathy described the impromptu meetings with the occupational therapist:

> Her time with Adam was individual and she saw him at the end of his day when I [was] getting ready to pick him up…she would see me in the hall and she would talk to me and tell me "Adam did good today" or "he did bad today, he wasn't cooperative,'' whatever…and "hey this is what we're working on, maybe you could try this at home."

Communication with the occupational therapist in the ECSE inclusion preschool was also, at times, in writing such as when the therapist would write a note in Adam's notebook: "They would write in a notebook and send it home to me to let me know if he had a good day or a bad day." In addition to the communication notebook, Kathy also liked that the therapists and teachers worked as a team in the inclusion preschool:

> We had a once a month meeting with all the therapists and find out what he wasn't doing and what he was doing, so that was the one thing beneficial about [inclusion preschool] is that I got to see the collaboration of all the therapists together and the teachers and to hear what progresses he was making and what progresses he wasn't making…it was so much [more] collaborative at the [inclusion preschool] on the therapists' part. It was just such a big collaborative effort they all worked together so well and told each other ideas.

Contact and communication in the public ECSE preschool was different for Kathy. She primarily communicated with the teacher, who told her how Adam was doing. The teacher utilized many forms of communication including home visits, formal progress notes, informal notes, and electronic mail:

> The teacher lets me know how Adam's week was. She'd come here twice a month and she'd send you emails and she'd send you a letter home every Friday, it never fails, let you know what went on during the week. So she was very involved with the parents and the students, which was very good. I get [progress reports] from the teacher, she puts it all together and then they [therapists] put in little comments, but that's the only communication that I get, so you figure there's nine weeks in a grading period, so at four and a half weeks and then at nine weeks I get a little note about how Adam is doing, other than that, there's no communication.

Kathy was somewhat disappointed in the limited communication that she had with Adam's therapists in the public preschool:

> So that's the downside of going to public school, you don't have that…I mean when I got the home visits from the teacher itself, you know, she would say, "oh Adam's doing really well…he's making progress" but she would basically tell me in the classroom progress, she's not gonna speak for the other therapists on what he's doing.

When Kathy was asked to describe her communication with the occupational therapist in the public ECSE preschool, she responded with heartfelt disappointment:

> We don't have much communication unless I see her out in town which sometimes I do, but other than that…I don't really hear from the therapist or she doesn't send me notes saying "this is what we're working on maybe you can work on this more at home." We normally don't see her unless we're going to IEP meetings…I don't hear from her, she doesn't let me know what's going on or anything like that. The times that I do get to see her and talk to her…she gives me information or tells me she thinks this is more beneficial to Adam. But since I don't see her regularly or hear from her regularly, I don't want to say anything bad about her because she's good with Adam, there's just not enough…I think there should be more communication.

Kathy felt that a barrier to her communication with the therapists in the public ECSE preschool program came from the administration (i.e., principal and assistant principal) at Adam's school. She had strong opinions of the administrators and shared why she felt they promoted barriers to communication:

> It's the administrators…they make it difficult, and I think they make it difficult for the therapists and the teachers to have a decent level of communication with the parents, that's where the break down I believe is at. I think the therapists and the teacher would be willing to do more and to talk way more if they knew their job wasn't gonna be scrutinized for it. That's a big fight with parents and the educators that run the school and I think that therapists just fall in the crack with parents because they want to do what's best for the kids, cause they worked with them, but they really can't come right out and say anything because they don't really want to lose their job because they like working with their kids but

> then the parents are really put in the crack because they don't know and unless the parents get informed or empowered by finding out information, you don't know what to do. Unless you know the law yourself or what the rights are or what to ask for, nobody at that school's gonna tell you, they're really not gonna tell you. Parents really try to trust the therapists and not the administrators and the special ed teachers that see our kids one on one all the time…but then they can't really say a whole lot.

Kathy also felt that a barrier to her communication with the occupational therapist in public ECSE preschool might be a lack of time on the therapists' part. Kathy considered adding a communication notebook goal to Adam's IEP but was not sure that the administrators would accept that:

> Because their [administrator] thing is "well they have to have planning time" and that takes away from therapy time, well I don't want to do anything that takes away from his therapy time so there's got to be some kind of way that you can get information besides twice a semester.

Ideally, Kathy would like more communication with the occupational therapist and she explored ways that might make this possible:

> Even if I came in after school to talk to the therapist, I mean that would be cool with me…then again, you would have to fit that time in, I don't know if that's possible to do that. Whether she send home like a little progress report once a week or…every couple of weeks just to say "hey, this is what we've been working on maybe you could work on these things at home in addition to at

> school." The speech therapist sends home key words every week…so maybe the OT could follow suit and do something of that nature.

Family Involvement and Participation

Kathy felt very involved in Adam's occupational therapy sessions in the EI program. Not only did Kathy participate in the therapy sessions, but she was also instructed in techniques to use at home:

> The first [OT] that I had …she gave me lots of pointers and "homework," she called it, to do while I was at home. She would show me what she was working on and she would do it a couple of times and she would have me do it so that when I did it at home I was doing it correctly, so she always had me do it so that she could see how I was doing it and to make sure that I was going to do it right. Just like in private therapy. I've always been involved with it…I would join in all the little things he had to do and we'd all be silly together. Because you see someone once a week for forty-five minutes and then you don't see them again, you don't want to not do therapy but one time a week because that's not gonna be beneficial.

Kathy did not feel as involved in Adam's public ECSE preschool class as she was in his previous inclusion preschool class, however she was willing to be involved in anyway she could:

> I don't work for just that reason, so if they ever needed me they know where I'm at. They can call me anytime. I send in stuff for the teacher all the time…things for parties, and anything that they want. If I see things special I send it to the class, or snacks, so she knows I'll be involved any way that I can.

Although she did not feel as involved in his class, she did have opportunities on a weekly basis to be involved in Adam's occupational therapy sessions at school. She recently went to his preschool class to observe circle time because she wanted to see what the teacher and therapists did there:

> It's an open invitation…they have a group session on Mondays with the PT, OT and speech and they do something fun that is with all three of them, and we can come and watch that any Monday that we want to.

When Kathy did go into the group sessions, it became more of a disruption for Adam: "I've gone in once or twice to the school and Adam does not do well when I'm there with him, so we've not gone in there with him." Kathy viewed Adam's behavior as a barrier to her involvement in his occupational therapy at school and felt that increased communication would be more beneficial because direct observation was disruptive for him:

> Adam, he would just get real clingy, so I just could not stay in there and when I'd leave he would cry, so it was, it was too much for me to go in there. Adam just did not handle us being in there, well, he didn't want to do what he was supposed to do. [He] just could not focus with us in the room. We're willing to participate in any way we can except to the point where it's gonna upset Adam for us to be there, so that's not beneficial to him, we think, to upset his therapy. So that's why I'm saying more communication from the therapist because if your child's not going to do well, you don't want to go in there because once they get in good with a therapist and they can work steady you don't want to

> disturb that. We rely on what the teacher or the therapist are telling us because he just does not want to work well when we're there with him.

There were other barriers to Kathy's involvement as well. She had strong opinions about her involvement in Adam's public ECSE preschool and felt that she was not as involved as much as she would like to be. She did not feel that parental involvement was promoted at Adam's school:

> I'm not sure how the school feels about parents coming in for a lot of the sessions…in preschool they said that anytime that we wanted to come in we can, but as they progress into the next grade levels, I'm not sure how they like the parent involvement in that. That's my perception and I've talked to other parents and they sort of feel the same way because the schools would rather us not be as involved because they're, well, my opinion is that they're gonna do as little as they can for our kids…they don't want our kids to participate in the testing and stuff like that, and it's almost as if they don't want our kids to get as much of an education as they can.

Kathy continued to discuss her opinion of the barriers that she faced as a parent trying to be involved in her son's preschool and therapy in the ECSE program:

> I really think that the schools want to get by with as little as they can for our kids with special needs and I feel like the therapists and the special ed teachers are limited as what they can do or say with us as parents because they work for the school system and they don't want to overstep their bounds and do or say something that can jeopardize their jobs…and if parents were always coming

> into the school, they would be seeing exactly what's not going on or what is going on, and I'm not so sure that the school really wants that known.

Kathy shared a story of an impromptu visit to the school from her and how the office staff handled it:

> One day I went to take him snacks to the class and…the lady in the office said "Oh no, you can't go in there, they're in instructional time; I'll have someone take it down for you." So you're not able to always go in that classroom you know, so you are limited as the exposure you're allowed to do.

Kathy was very involved, however, in the development of Adam's IEP. She explained how she prepared for the meeting and asserted her opinions to get what she wanted for Adam:

> Well, I research. They sent home his IEP this time and I didn't like the way that it looked. It wasn't as academic as I though it should be, and if he was going into a regular Kindergarten setting, he would have a lot of academics, and I felt that they were limiting him because he doesn't …orally he doesn't have a lot of vocabulary, as much as they would like and attention and focusing and stuff, they didn't think he could handle as much. I think otherwise. I see him at home everyday, and I went through the SOL regulation book to see what was required for Kindergarten, well, I picked out the ones I thought that he could handle that weren't on his IEP and I added that to that.

Kathy also shared how she was involved in determination of Adam's related services. She asked for changes in the amount of time he got for PT, OT and speech. Kathy shared that she was comfortable making changes to his IEP and appeared to be becoming increasingly more comfortable with advocating for Adam, but was concerned she was going to hurt the therapists' feelings:

> I did feel comfortable to an extent but I know they had put in a lot of time on this collaborative effort into the IEP and I felt like I was hurting their feelings by researching and doing this and asking for this and that, cause I didn't want to hurt their feelings, I just felt like he needed more …but they seemed OK with it, so they told me not worry, I didn't hurt their feelings. I've talked to the therapist…when we had our IEP meeting the OT talked to me and…I was feeling bad for changing all the goals on the IEP and she said "don't feel bad, you're the advocate," so you know…they make you feel good.

Kathy shared what she felt her ideal involvement in Adam's occupational therapy at school would be and what she herself would be willing to do to be involved:

> I would love to be involved as much as they would let me. Occasionally I think that it would be a good idea for the parent's to come in and see exactly what the therapist is doing…so that we can maybe get some techniques that we can use at home 'cause sometimes it is easier to see it than to hear it. If it [his OT session] was individual, maybe he would do better, if he was out of the classroom setting and he was just focusing in on the therapy itself…and I may be able to pull his attention in a little bit more so that she can get him focused too, but I'm not sure how they would work that at the school. I'm willing to do anything. If the therapist sent home a note, "hey work on this," I mean, we'll do that, where if she needed us to come to the school and see him, we would come, all she'd have to do is contact us.

Kathy sought therapies outside of those provided by the school system to supplement Adam's therapy program at school. She shared why this is important and how it gives her a sense of involvement:

> He gets private OT during the summer and he gets private PT during the summer, and he get private speech all year…in addition to what he gets at school. With private therapies, I've gone in to and done a lot of the session with him there.

Disappointments

Kathy had many disappointments with Adam's services in the ECSE inclusion preschool. She shared her feelings and disappointments surrounding this issue:

> [In inclusion], they [OT and special education teacher] weren't at the school all the time so they couldn't help him as much; and his peers weren't as accepting as we thought they would be and neither were the teachers. So that's why we pulled him out of the [inclusion preschool]…we found it did more harm to be in [inclusion], for him it was too overwhelming. We thought we were doing the right thing at first doing [inclusion] because we wanted him with his regular peers, only there with the special ed teacher and the OT and all them coming in. He wasn't happy there and he was crying and didn't want to go to school, so it wasn't a good environment that last half of year. [Now] he's happy to go to school, he's happy to come home and that's all that's important to us. It was time for him to go on.

Kathy shared that she was also disappointed in the administration in the public ECSE preschool. She felt that they set limitations on children with disabilities there, such as the level that they participate with the general education at that particular school:

> The principal and the vice principal…because they're the ones that decide what programs can be at that school and how much participation they want the special ed kids to have in that school…so it's hard to be the parent of a special ed kid these days.

She was also disappointed with not getting all the information she though she should have during the transition process. It appeared that decisions made by the school system did not recognize that the timelines they establish may impact a families' ability to transition as smoothly as possible:

> They couldn't even tell me whether he was going in the p.m. or the a.m. so there's a lot of things that we have to wonder [about] over the summer, even though we've got the IEP written, of what's gonna happen.

Finally, Kathy was disappointed in the length of the occupational therapy sessions in the public ECSE preschool. This left Kathy unsure of the value of occupational therapy in the ECSE preschool due to time limitations:

> Because…you see a kid for 20 minutes and the first five minutes you're trying to get the kid to calm down…or get his attention. I know with some kids, and even like Adam, they're motor planning is not real well and focusing is hard, so trying to get them to focus and get their attention directed takes a lot of time so if you've only got twenty minutes to work with that child, you're doing more grabbing their attention and trying to direct them than therapy.

Summary

Kathy's case revealed eight categories. Kathy was initially excited about the upcoming transition to ECSE inclusion preschool and expressed uncertainty of the unfamiliar world of preschool special education in fears and feelings about impending transition. The EI service coordinator assisted Kathy with the initial activities for the transition, however after that Kathy felt on her own and somewhat abandoned, prompting her to seek guidance and support from a network of friends who also had children with disabilities and who had "traveled the path" before her in preparation for transition. The occupational therapist in EI was especially beneficial for Kathy in helping her to adjust and accept Adam's disability. She counted on many professionals to guide her in the right direction during this time. Kathy recognized that the occupational therapist shifted her role as Adam progressed through the various programs, initially working on developmental skills and eventually addressing skills needed in the classroom environment prompting her to recognize the importance, role and benefits of occupational therapy.

The context of Adam's occupational therapy also changed as program settings changed. Kathy liked the individual sessions that Adam received in EI; however she felt that the OT in public ECSE was doing what was best for Adam by seeing him in a group situation in logistics of occupational therapy. Kathy especially enjoyed her working with Adam's first OT in EI, she felt like she was a friend, a friendship she had not had since with Adam's OT's. She shared that her feelings toward Adam's OT's was really a "personality thing," she either "meshed" with them or she did not, thereby describing her relationships, feelings and satisfaction. For Kathy, communication with the OT was more frequent than with the OT in the other programs they have been involved with. Kathy attributes this to actually “being there” during Adam’s sessions, and being able to share ideas that helped both Adam and the entire family. Since transitioning to the public ECSE, Kathy has had limited communication with the occupational therapist. This lack of contact and communication has left her feeling disappointed and alienated from the therapeutic process. Since transitioning from EI, Kathy no longer participates in Adam’s OT sessions. Attempts to observe sessions in the ECSE preschool resulted in counterproductive behaviors from Adam, making therapy ineffective. Kathy has since taken a more assertive role in the development of Adam’s IEP, asserting her opinions and desires that promote family involvement and participation. Kathy questioned the value of occupational therapy services in the public ECSE program due to Adam’s limited time with the therapist. Additionally, the inclusion ECSE experience turned out differently than Kathy expected. Kathy felt that peers and teachers were not as accepting of Adam as they originally hoped, highlighting her disappointments following the transition to ECSE.

Courtney and Jamie

Background Information

Courtney was married and the mother of two girls, ages six and three. Jamie, the youngest, had hydrocephalus as well as a brain malformation. Jamie also had a severe eating disorder that caused her to refuse to eat and resulted in the necessity of gastronomy tube (GT) feedings. The interview with Courtney was conducted in her home and began as Jamie arrived home on the bus from school shortly after my arrival. Present for the interview was Courtney, the researcher, Courtney’s daughter Jamie, as well as Madeline, the four-year-old daughter of the researcher. Courtney felt that having Madeline included might help to occupy Jamie. The interview was audiotaped and lasted approximately 60 minutes and was conducted primarily in the family room of the home. The recorder was turned off during a portion of the interview so that Courtney could get Jamie's feeding set up. A brief follow up interview lasting approximately 11 minutes was also conducted and audiotaped over the telephone to further explore areas of interest as well as to clarify Courtney's responses to inquiries during the initial interview.

Jamie was almost four years old at the time of the interview and was completing her second year in the early childhood special education (ECSE) program. She was eligible to receive special education services under the classification of developmental delay. Courtney described Jamie's need for occupational therapy as:

> She's significantly delayed in PT and OT, it's motor, gross and fine motor. Her fine motor skills are so delayed because as she didn't crawl, she was very delayed…she'd never feed herself, never put food in her mouth, because she couldn't use her hands.

As part of her ECSE program, Jamie attended the local elementary school for half a day, each school day. Jamie also received occupational therapy for 60 minutes a week in addition to a group session as well as 60 minutes weekly of physical therapy. Jamie was also fed periodically during the week by the speech therapist.

Jamie transitioned to the ECSE program in October when she was two years old. Prior to her ECSE placement, Jamie received services through the early intervention (EI) program in their county. In this program she received occupational therapy services "every day practically." Courtney explained that Jamie received occupational therapy both through the EI program as well as through their private insurer. Because the OT was the only outpatient provider in their area, Jamie was served by the same occupational therapist through both reimbursement systems. Jamie continued to receive occupational therapy services by this same therapist throughout her EI program. Jamie also attended a weekly playgroup on Wednesdays at the EI center and an occupational therapist would work with Jamie in that group as well. Jamie also received physical therapy and speech therapy services as part of her EI program and the family received respite one time each week at the EI center.

The transition from EI to ECSE actually started in July when Jamie graduated from the EI program and started an intensive day feeding program at a nearby hospital. Jamie then started the ECSE program following her completion of the feeding program near the end of October.

Fears and Feelings About Impending Transition

Although Courtney knew that she was able to wait until Jamie was three to transition, they made the decision to transition her early "because they felt that she needed more stimulation than she was getting in the early intervention, specifically because of her verbal [abilities]." Courtney shared additional reasons why she decided to transition Jamie before she turned three years old:

> Because cognitively she was way beyond these other kids and she [service coordinator] said she just needs to be stimulated…she needs to go move on…she said we can keep her until she's three but she would definitely do better there and she was right. For the socialization…just the variety, she's so social

> and so verbal she had people to talk to and …she was gonna get a fuller four hours, where in the [infant] program…one hour a week is play group and then whatever services I got at home.

Courtney did not have any concerns about Jamie entering the ECSE program and was comfortable and actually excited with the upcoming transition. She was ready for a break from the day-to-day care of Jamie and felt that the socialization that Jamie would receive would be very beneficial to her:

> I think I was pretty comfortable and emotionally ready. I was excited. I so much needed that break…and everyone was so confident that it was going to go well and everything. I was not as apprehensive about entering this program.
>
> She [Jamie] loves it; I mean she never once had a problem with stranger anxiety.
>
> I wasn't concerned cause my service provider at the early intervention program really felt Jamie would benefit from transitioning out of [the] infant program.

Courtney also felt comforted by Jamie's level of comfort with the ECSE staff. The transition was made easier by the attitudes and receptiveness of the ECSE program staff. She recounted Jamie's reaction to a meeting the ECSE program provided to allow the parents and students to meet the teachers: "Everyone surrounded me [and] in a few interactions that they had with Jamie…she was so comfortable then we thought she's not going to have any problem at all."

Preparation for Transition

At the time that Jamie was leaving the EI program, Courtney was busy making preparations for Jamie's day feeding program. The feeding program was offered by a nearby children's hospital and provided services by specialists trained in feeding disorders. The program provided an intense feeding protocol for Jamie from morning to night, in attempts to alleviate some of the difficulties Jamie and Courtney were experiencing surrounding mealtime. This feeding program occurred in the mist of the transition from EI to ECSE and Courtney shared how the timing of this impacted the transition for the family:

> It wasn't much of one. She graduated [EI] in July and…she started the feeding program…in July, [a] day program. I think our transition is more unusual than most because she didn't start the school year in September and it perhaps would have been different, but I don't know what …it would have been. She entered a program, a routine that was…everything was already established, kids already knew each other for two months and here comes a new kid, she did very well, we all did very well. [The late start] actually may have benefited us. Because now that…all the other kids issues [were] out of the way, now we can focus on Jamie's needs because she came in at the end of October when there weren't any other new kids.

Courtney explained that the EI staff explained the transition to her, but after Jamie graduated EI, they were no longer involved in the transition. Courtney communicated with the ECSE teacher during the time that Jamie was in the feeding program:

> It was the teacher we were communicating with…letting her know what day she's gonna be starting…we really didn't sit down until after she started, we kind of talked about her goals and her IEP and all. They were just saying, "We can't wait till she comes, can't wait till she comes."

In addition, Courtney attended a gathering at the ECSE preschool to familiarize Jamie with the ECSE staff and also visited the ECSE preschool where she "found out what to expect."

Courtney was unsure about the communication that occurred between the EI and the ECSE program. Courtney did convey that the EI program and the ECSE preschool work very closely together: "They're right across the street from each other practically…they work very well together." She didn't feel that the OT in either program was very involved in the transition process. She speculated about the communication that likely occurred between the two programs:

> I'm sure that our service provider filled them [ECSE staff] in on everything. Probably spoke to them about not only Jamie but also what to expect from mom (chuckle) you know. I'm a very pushy aggressive mom…you know, on how to deal with me.

Courtney felt that she was responsible for most of the preparation for the transition. Courtney went to Jamie's preschool the first week of school to ensure that Jamie was fed properly according to the protocol that was given to her in the day feeding program. She explained the preparation that was necessary and her role in the transition preparation:

> I went the first week of school. I was there everyday…every day I was actually feeding her until they figured out what we were gonna do about that. We had left a very structured protocol [in feeding program]…that we planned to do [at school]….I brought a high chair into the school, her tapes, music tapes, her toys, all that stuff…we had a very, very regimented feeding protocol…we had to be

> very, very consistent at that point because we'd gone nine weeks, we'd been trained, so every meal had to be done exactly the same, so I went to the school that first week and fed her every meal.

Courtney also trained the ECSE staff, including the OT, in the feeding protocol and felt that the OT was somewhat defensive. This led to her feeling awkward with the training:

> The second week I trained them. They observed me and then I let them do it and I observed them. It's kind of weird cause you're teaching the OT what to do and…she would say to me… "I'm very experienced feeding," well, she was never experienced feeding somebody like her [Jamie].

Importance, Role and Benefits of Occupational Therapy

Courtney felt that her occupational therapy services in the EI program were very important, not only for Jamie but for herself as well:

> Very, very [important], I wouldn't have made it through the day without those people coming here everyday…I would have, but it was so hard. Just not having to feed her that one meal was so worth it. Because it [OT] was so needed…we needed it…I was gonna be admitted.

Courtney described her perception of the role that the occupational therapist served while Jamie received EI services. She saw her main role as "respite and feeding." However she also saw the OT as service provider, counselor and teacher. As a service provider and teacher, the OT in EI was skilled in feeding Jamie and teaching Courtney helpful techniques:

> My OT was through [EI] and [the] insurance company and…they guided me. These people were specialists and could work on developing…her fine, gross

> motor skills, her speech, and all that. She [OT] was pretty good about getting feeding over with. We always tried to use diversions and…she would teach me like, she'd go behind her, and feed her from behind cause she didn't see…and she taught me those kinds of things to do. And [OT] also worked…as much as she could, she tried to work on her fine motor skills.

The role of the OT as counselor was also evident as Courtney recounted her feelings and emotional state and how the OT in EI helped her through that time in her life:

> You have to understand, my life at that time was an emotional mess, and I was on edge all the time and I was so stressed out because of my daughter not eating, and [the OT]…she always tried to just help me understand that…that this is a slow process, she's been here, she's seen these kids before…she always would say to me, "by the time she's five" and I would say "oh my God." But she, she knew and she would always say you know, "she's here, she's alive, she's gaining…you're doing everything." She was almost like a counselor for me.

The OT in the early intervention was also like a respite care provider for Courtney during this time. She described how the OT provided respite for her from the exhaustive process of having to feed Jamie every meal:

> She was a respite caregiver; anybody that came through that door to take her off my hands for a while was a respite caregiver. I needed to get away from her so badly…it was so stressful, before she got her feeding tube…this child was borderline dehydration every day of the week…it was a major, major ordeal every feeding and I was feeding her five times a day for thirty minutes and I

> looked forward [to someone else feeding her], that was respite for me. And to have someone else feed her and [OT] would feed her. I think [she] would have preferred to be doing more with Jamie's motor skills, her fine motor skills, but my needs at the time was to get respite from feeding her.

Courtney also described the important role that her service coordinator played during her time in the EI program:

> They have…service providers, your service provider really is your...helper…my service provider happened to be a speech therapist. She was doing speech with Jamie and feeding. My service provider [treated Jamie] as if she was her, her kid, she was incredible. And I still use her as a resource and I still stay in touch with her.

Roles of support providers were also evident as Courtney discussed her experiences with the EI team, including the OT:

> We see her, the OT was, as I look back, she just…really wanted us to relax and try to take it easier about things and know that in time it will come together. She was willing to do anything really, whatever I needed, she'd stay longer, she'd go the extra mile. [The EI staff], they recommended counseling; [my husband] and I went to counseling…and we had a weekly parent support group and we…talked about things like that then.

In addition to the EI staff, Courtney felt that she also received support from Jamie's pediatrician. Her pediatrician was "behind me one-hundred percent and if I felt that she needed more of anything she would order it."

Courtney also felt that OT in the ECSE program was important, however she differentiated the level of importance that OT served in meeting Jamie's feeding needs from that of other motor milestones. Initially, Jamie's feeding and walking came first on the level of importance for Courtney: "We spent so much of our time and energy on the walking issue and the feeding issue that the fine motor issue was not on the high totem pole." The level of importance of OT in Jamie's ECSE program has changed during the second year for Courtney. She felt that OT was very important during that second school year:

> It's very important specifically because her OT delays…her fine motor delays exceed her gross motor delays. [Previously] we were putting a lot of focus on PT because we wanted her to walk…not as much focus was going on OT…we need to refocus now on OT. Now that her gross motor is catching up to her age, now the fine motor's more significant of the delay, so now we need to focus on that.

Courtney described her view of the role of the OT in the ECSE program. She perceived the OT as a team member and working on fine motor skills, adaptive skills and feeding with Jamie:

> She [OT] has a very active role in the preschool; she works with lots of kids. Her role was…part of the team, a therapeutic team. What she did with Jamie was she worked on fine motor development…puzzles, and turning jars, and doorknobs and her writing skills and…that was her area. Her area was fine motor and feeding. She's working on what's Jamie doing with her hands…how is she developing in the use of her fingers. She's focusing more on…getting her

> to use her hands, games…putting pieces in place and anything to use her…hands.

The OT also fed Jamie at school her first year in ECSE. The OT and the speech therapist fed Jamie on different days and Courtney had mixed feelings about this role. Courtney often felt that development of Jamie's fine motor skills were being overlooked, to a certain extent, at school because of her feeding issues. She explained how the feeding occurred at school and her feelings about that:

> Because her feeding issues were, are so severe, "extensive," that they needed someone to feed her and because of not having extra manpower to help…some other person to feed her, OT was feeding her lunch and that was considered her OT. [We had to decide] what was more important, she had to get food in, [and] either we had her tube fed at meal time or we had to work on her feeding. From the beginning the OT could do her…fine motor and adaptive skills and have somebody else feeding her. So for sixty minutes a week of OT, she got really maybe twenty cause the other time was used for [feeding].

Courtney further explained that Jamie did get attention from the OT briefly during group time, but primarily Jamie's OT time was spent on feeding. Courtney also explained that the role of the OT in ECSE is now shifting to focus on fine motor and adaptive skills. She credits this shift both on Jamie's development and also on a new ECSE staff member that was hired to feed Jamie:

> Now that has changed, this school year they now have a staffer who feeds her and now the OT is actually working on her fine motor and adaptive skills. Now

> we're going into a new page with OT where she will be getting more, more typical, I guess, OT services.

Courtney also discussed the role of the ECSE teacher and viewed her role as being holistic. She worked on all of Jamie's skill areas, however Courtney saw a difference in the role of the teacher compared to that of the OT: "The difference is…the teacher's working on cognitive…it's holistic, they're doing everything, but the teacher is in addition working on cognitive development."

Although Courtney did not see Jamie's occupational therapy services in ECSE as beneficial to their life at home, she has seen a change in the benefits that Jamie is deriving from her OT in her ECSE program: "I really don't think it was very beneficial to her last year…now this year it has been…her fine motor is improving but we still have a long ways to go."

Courtney was able to identify differences between the EI program and the ECSE preschool in terms of the amount of services Jamie received and the focus on Jamie's needs:

> We got a lot more [in EI]…[OT] was coming at least two times a week for an hour…at least two hours a week, probably more. In the preschool the OT's working in groups a lot and Jamie wasn't necessarily getting the one on one. I mean she was only getting an hour a week one on one…you might be working with one particular child but they're in a group…whereas the early intervention OT was…focused only on your child because she's alone with your child.

Courtney felt that the amount of time that the OT spent with Jamie was less because so much time was spent on feeding and not enough time was spent on fine motor or adaptive skill development: "Oh it was definitely less. It was the same amount of time but it wasn't spent on adaptive and fine motor skill development."

Courtney also identified differences between how goals were established and addressed in EI compared to ECSE preschool:

> Her goals with early intervention were you know, I was there when she was getting her OT…and different when you have PT and OT services at home, you kinda set goals with your therapist and you work with them. The goals are much more long term [in ECSE] and you make baby steps through the year…and you don't necessarily reach those goals as quickly as you would like.

Logistics of Occupational Therapy

The locations of occupational therapy services were different between the EI program and the ECSE program. In EI, Jamie received her occupational therapy in her home at a time that was convenient for her family and coincided with her feeding time. The OT went to their house to feed her. In addition, OT was provided for Jamie at the early intervention center, where she participated in a playgroup one day a week. In the group, both OT and PT participated to facilitate developmental skills.

Courtney is not as sure about the time that Jamie's OT is scheduled in the ECSE program: "They're on a schedule but it changes based on staff availability and what kids are there that day." She explained how the scheduling worked:

> In the beginning of the school year I wanted to know when she was going to get this, this, and this and they always say it's kinda hard to say because from one day to the next and with all the different kids that they work with, they fit things

> in, so it’s not Monday’s at ten she gets this and Wednesday’s at three she gets this…it doesn’t work like that.

Courtney also explained that Jamie’s OT sessions occurred primarily in a separate OT room in the ECSE program. She described how the location also changed periodically:

> She gets taken out of the classroom and then one on one…in a OT room. She sometimes will get it like having to work with her out on the playground…with toys and swings and whatever the kids are doing out there…always guiding them, working…plus she gets it in the class when they do group activities.

Relationships, Feelings and Satisfaction

Courtney was satisfied with the occupational therapy services that she received in the EI program. She felt that is was more directed, intensive and frequent than what she received in the ECSE program. She felt that the OT had extensive experience with children with feeding problems and “she knew what she was doing.”

Courtney also shared her feelings about occupational therapy in EI. She described a process where she and the OT learned together:

> We worked, she a lot, she did research to get herself up to speed and she had tricks and songs she would play and she’d say, “let’s try a lemon,” that kind of stuff. It was a challenge for my OT at home because [she] hadn’t worked with an infant for a very, very long time and on one whose feeding problems were as significant as Jamie’s.

She also felt like she was in control of the services in EI: "I drove the services…it was me dictating more than anything because I was the one who needed what needed to be done."

Courtney did not feel that the OT in EI was as goal oriented as she because she knew that skills would come with time. But for Courtney, it was much harder to wait. Courtney experienced much frustration and she shared her feelings about that:

> She knew in the back of her mind that this would all happen with Jamie. I didn't think she was as goal oriented as me, but again maybe they just know better because they know how long it takes and that you have to set small realistic goals and they don't get frustrated like I do. Of course, it's not their child either.

Courtney also described her relationship with the OT in EI. Jamie had the same OT the whole time she was in that program:

> We [are] such different people, we had a good relationship. I had a more personal relationship with the OT in early intervention in that I could be really honest with her…she was more honest. I felt like I could talk to [EI staff]. She tried to relax me…I'm very intense and fearful about…Would Jamie ever eat and stuff?" Where she knows it kinda, when these kids turn five it all starts to kick in, so my relationship with her is very good.

Courtney felt that Jamie was "in good hands" in the ECSE preschool and that the staff there were doing "wonderful work with her." She felt that the staff wants to be accommodating. However, she reluctantly described her feelings about occupational therapy in Jamie's ECSE program as well as her relationship with the occupational therapist:

> I feel the occupational therapist she had for the last two years, I would have liked her to be more aggressive…she was very laid back…very, kind of easy going, slow moving kind of person. She knows what she's doing, but…as far as my personality goes, I like people who are a little bit more driven. The OT at the preschool was a lot more…she saw Jamie's iddy biddy steps as big steps. She was always more pleased with what she was doing than me. For me, it was always not enough, she could be doing more, and [the OT] was always like "come on, she's doing great." It's a personality thing.

Courtney felt that she had a "pretty decent relationship" with the occupational therapist in ECSE preschool, but felt it was very different from the relationship that she had with the OT in EI. She described her relationship with the OT in the ECSE preschool as "one of mother of child…we didn't have a personal relationship at all."

Courtney also felt that the OT in the ECSE program was not as successful with feeding Jamie and that she really did not want to feed her:

> That was part of my angst with her [OT] that she, I'm sure, didn't really want to be feeding her. The OT…at the preschool has the least success feeding her of anybody. From the beginning to this very day, the OT in…her school had the least success feeding Jamie out of anybody. And whenever…[OT] fed Jamie it didn't go well. Well, Jamie threw-up all the time and Jamie, I think, she threw-up more for [the OT] than for [the speech therapist].

Delegating the responsibility of feeding Jamie to someone that wasn't as successful was initially difficult for Courtney, however in time she adapted:

> See, I used to stress over it and go “oh my gosh, [the OT’s] feeding her today, damn, she won’t get any food in her,” now I’m like “if she misses this meal, no big deal,” because she’s come so far, I’ve come so far. But still, I know when [OT] feeds her it’s not going to be very successful or if she does, she takes an hour to do it, but that’s up to her.

It was also evident to Courtney that Jamie was not making as much progress with her fine motor skills as she would have liked in ECSE:

> I could see at home that there was not as much progress in the fine motor areas as I would have liked…she wasn’t as aggressive working with her. She [OT] works on what she wants to based on what she feels Jamie needs because I’m not telling her what I want her to do.

During a summer school session that was provided by the local school division, Jamie received occupational therapy by a different occupational therapist. Courtney felt that the OT that saw her in that program was “phenomenal”. She felt that the PT and the OT that worked with her that summer really facilitated progress: “In that one month, they worked with her so much and there was improvement in one month, over what they have been doing in the school year.”

Courtney felt like the school was willing to work with parents. She felt that the OT would work on things that she wanted Jamie to work on, and that if she wanted more services for Jamie that she would ultimately get it. She was, however, somewhat disappointed in the amount of time spent on feeding Jamie. She would have preferred more time spent in OT on fine motor skill development. She read from Jamie’s IEP during the interview and it was clear that Courtney was disappointed: “It says two thirty minutes a week, so she's been getting less than that…and that's because…of the feeding."

Ideally, Courtney would like to have an OT that is more aggressive with working with Jamie but felt that she had to accept the therapist that was provided by the school system in ECSE: "I think I would love to have somebody more aggressive working with her and that's not the case; she's in the school and you get what you get."

Family Involvement and Participation

Courtney was as involved as she wanted to be in Jamie's occupational therapy sessions in EI. She sometimes got involved in the session and took part with her in the therapy sessions and "saw what she [OT] was doing with her." Courtney described her typical involvement in OT in EI and steps she took to work with Jamie when the OT wasn't there: "From week to week I was working with OT specifically and…I had a lot of input. I imitated basically…and I observed what they were doing and then I'd just copy it."

Courtney was not as involved in the development of Jamie's IFSP while in the EI program. She did not know how to be involved and was overwhelmed with the day to day care of Jamie at the time: "I didn't know…really quite honestly…I was in a state of despairs…I didn't…they helped, they did it, pretty much, and I said OK."

Courtney's involvement in Jamie's occupational therapy program in ECSE was limited to participation in classroom activities such as parties, plays, activities, and fieldtrips. Courtney did not see the therapists that often and "didn't go there a lot." She felt that she could call anytime and show up when she wanted. She did pick Jamie up weekly for an appointment, but admitted "I don't spend a whole lot of time in her classroom." On one occasion, however, Courtney planned an observation and on another occasion engaged in an impromptu observation of Jamie's occupational therapy session. She described what she observed: "She physically played on the floor with her and did the puzzles, this and that." Courtney shared that she preferred to see what goes on when she's not there, so she tries "to take a back seat and then talk to her [OT] later about it." Courtney felt that she was more involved with PT because Jamie's goals were more specific and she was "more on top of it."

Courtney explained that she should be more involved and that she felt that if she were more involved she would see more progress:

> I should be more involved…based on my standards for myself. I think an IEP should be looked at every month and I haven't been. And if you, as a parent, are on top of things, that's when you get action. I talked with the OT and I said she [Jamie] needs to be doing more with her hands…they are working on it, but when the parents get more involved and are more verbal about it then they will focus more and they'll be more goal oriented if…you are present, which I haven't been much.

Courtney shared that she felt ashamed at times because she's not as involved: "I guess sometimes…I feel ashamed that other moms are there a lot more than me." She also explored reasons that she was not as involved and potential barriers to her involvement:

> I planned on doing [visits to classroom] once every other week, but…I had to go to work full time in September because my husband was out of work and then

> through the following winter I didn't because I was working, and then when spring…rolled around I hit a wall…and I needed a break…she wears me out.

Courtney also felt like she knew how to help Jamie and knew about her feeding techniques: "With OT, so much of it was feeding until recently that I felt like I've been there, done that…I can teach them…I have [taught them]." Courtney was also concerned that her involvement would cause Jamie to act differently when she was there, and she wouldn't get a true picture of a therapy session. She explained that now that she's focusing more on OT, that she is going to have more of a presence when the new school year starts.

Courtney has been very involved in Jamie's IEP development and monitoring in the ECSE preschool: "We established goals on her IEP and then…during the year we'd kind of keep track of what she's doing." She described how the IEP meeting was conducted and how she was involved:

> They had theirs [IEP goals and objectives]…we sat around a table and they listed what theirs were and I gave my answer as to whether I agreed or disagreed or wanted them differently. And for the first IEP, I was not experienced so I didn't know that you set a goal for the year…but now…I know more so when we do our IEP in September I'll…I'm thinking that I'll have some coaching this summer about…her IEP.

Contact and Communication

Communication with the occupational therapist while in the EI program was primarily verbal for Courtney. The OT was responsible for providing written daily reports that summarized her visit, however it was the PT who provided Courtney with written instructions. Courtney shared instances of communication with both the OT and the PT:

> The OT was here; they were in my home…every day, every other day…she had to do her daily report. I always said to them, "So what's my homework?" With [OT], she was here so often it was from one day to the next or every other day. But with PT it was more she came once a week or twice a week for an hour and I'd say, "Ok…what am I working on for the next few days?", and she would tell me. The PT would bring me charts…sketches of different types of things we should be [doing], exercises and stretches. Then we'd all be following the same [protocol]. We didn't have that with the OT and pretty much with the feeding program we were, doing…oral motor exercises, and I had a guide.

Courtney did not feel the necessity for written information from the occupational therapist in EI as much as she felt it necessary to get written information from the PT. By having written instructions from the PT, Courtney felt that she could better communicate to her husband specific instructions so that he could also work with Jamie at home.

Courtney communicated with Jamie's OT in ECSE in varying ways. Because she picked Jamie up weekly for an appointment, she often had the opportunity to engage in an impromptu meeting with one or all of Jamie's therapists:

> Basically, the way I connect is [each week] I pick her up to take her to [her appointment], for outpatient therapy and I catch [one of her therapists] in the hallway. I would just say, "What's going on with Jamie? What are you working

> on?…how's she doing?" I mean each of the people…would talk to me about their specialty.

There were also occasional pre-planned formal meetings throughout the school year that the occupational therapist was involved in that allowed opportunities for communication:

> Yeah, one in the beginning of the school year, and we had another one a few weeks ago…actually we had three meetings this year because we had a meeting about her feeding and the OT was there for that too.

Additionally, Courtney communicated with the occupational therapist in the ECSE preschool through written notes. At times she would write a note to convey to the OT that she wanted something addressed or to "bring something up." The OT also wrote Courtney a note when she fed Jamie: "When she feeds Jamie, she writes me notes, she writes me long notes…how it went, what happened today, blah, blah, blah." In addition to written notes from the OT, the PT that worked with Jamie in the ECSE preschool also sent home written instruction for her to work on.

Summary

Seven categories were identified in Courtney's case. Courtney felt that Jamie was ready to transition to ECSE; she was excited at the prospects of having better role models for Jamie and getting the much needed respite for herself, highlighting her fears and feelings about impending transition. At the time that Jamie "graduated" from EI, Courtney was busy preparing the family for Jamie's feeding program. Jamie started the ECSE program late because of this, however Courtney felt that it worked to Jamie's advantage, as she was able to enter a preschool program that was already established.

This delay did, however, leave the onus of preparing for the move solely on Courtney. She was left to make the contacts with the ECSE staff and train them in the very intense feeding program in preparation for transition. In the early intervention program, the occupational therapist provided much needed respite from the exhaustive process of feeding Jamie every meal. The OT became someone who Courtney relied heavily on for respite, teaching her techniques of feeding, and providing counseling for Courtney in dealing with Jamie's significant developmental and feeding needs. As Jamie transitioned to the ECSE preschool, the OT services began to shift to more "traditional" services, incorporating fine motor and other sensory strategies, thereby providing less benefit to the family as Courtney described the importance, role and benefits of occupational therapy.

The context of occupational therapy has also shifted with the transition for Jamie. In EI, Courtney explained that it was in their home at a time convenient for her. Now, in ECSE, she doesn't really know when OT occurs, it's not on a set schedule. This seemed to bother her at first, however now she understands that when Jamie is fed, it occurs in a separate room, but at other times it may be in the classroom, playground, or other area of the school that pertain to logistics of occupational therapy. Courtney felt that she was on a more "personal" level with the OT in EI and described a process where they learned together. In contrast, Courtney did not gain a sense of friendship with the OT's Jamie has had since transitioning to the ECSE program. She would have liked more aggressive therapy for Jamie and described feelings of angst with the OT in ECSE for not being as aggressive, which negatively impacted her relationships, feelings and satisfaction with the OT services in ECSE. Courtney participated in OT while

Jamie was receiving EI services and took steps to work with Jamie when the OT wasn't there. She did not participate in the development of Jamie's IFSP, however, as she was overwhelmed at the time and was not really sure how to be involved. In contrast, Courtney's participation in ECSE was limited to attending parties, fieldtrips and plays, although she takes a much more active role in the development of Jamie's IEP. Courtney admitted that she was sometimes ashamed of her limited family involvement and participation in ECSE. Courtney enjoyed the day to day conversations she had with the OT in EI, this allowed her to carry over therapy techniques at times when she wasn't there. In ECSE, she engaged in impromptu meeting with the OT when she picked Jamie up for appointments. This allowed her to stay abreast of how Jamie was doing in therapy. In addition, she received lengthy notes from the OT in ECSE when she fed Jamie, highlighting the contact and communication that occurred.

Summary of Cases

To summarize, a total of seven interviews were conducted, five of with the mother only and two with both parents present. Interviews were conducted using an interview guide and were audiotaped. Interviews were transcribed verbatim, coded and analyzed using an inductive approach. Each interview is presented in a case report highlighting a total of nine categories that emerged during the content analysis process. A cross-case analysis was then conducted to highlight the six categories that were common across all seven cases. Common themes that emerged from this inquiry are presented in integrated fashion in the final chapter.

CHAPTER V

DISCUSSION

Discussion of Results

Purpose of the Study

The purpose of this inquiry was to investigate parent perceptions of occupational therapy services in early childhood special education programs following transition from early intervention programs, and how parents' perceptions may have changed over time. Chapter IV presented the seven individual cases and the categories that emerged from each case. This chapter will discuss the cross-case analysis of those categories and the inferences that helped to inform the final themes. While examining these categories it is important to note the three key variables: variation in the severity of their child's disability, program options, and parental acceptance of their child's disability. The seven participants had children with varying disabilities ranging from mild disability to severe disabling conditions, thus varying their experiences and approach to the transition. Participants were not all given the same programming options during the transition, depending on their locality. In addition, participants varied in their level of education as well as varied in their level of acceptance of their child's disability. A total of four themes emerged from this inquiry which have implications for occupational therapists practicing in early intervention and early childhood special education settings, as well as for other professionals such as teachers, administrators, physical and speech therapists and paraprofessionals working in these settings. These four themes help to answer the questions that guided this study, specifically:

1. How do parents of children who formerly received early intervention services and who currently receive early childhood special education services view the role and benefits of occupational therapy in their child's preschool program?
2. How do parents conceptualize the differences between service delivery of occupational therapy in early intervention and early childhood special education?
3. How do parents describe the type and extent of communication with their child's occupational therapist as school? How has this changed from that of early intervention? How do parents describe the effectiveness and their level of satisfaction with this communication in comparison to the effectiveness and satisfaction with the communication they had with their child's OT in early intervention?
4. How do parents describe the type and extent of their involvement with their child's occupational therapist at school? How has this changed from that of early intervention?
5. In what ways can occupational therapists help make the transition process flow smoothly for parents and children transitioning from early intervention to early childhood special education?

Cross-Case Analysis

The following represents the examination across common categories and the high level inferences that were derived from the data that allowed themes grounded in the data to emerge. The process of examining the low level inferences for each common category allowed the researcher to ascertain prominent features of the category that were evident to anyone reading the data. By examining the high level inferences in each category, the researcher was able to combine both the low level inferences and high level inferences to attach meaning to those inferences that may not have been readily evident to those not intimately familiar with the data. For instance, the researcher was able to combine the emotionality of the participants and the knowledge and experience that the researcher brought into the situation to exemplify the inferences derived.

The cross-case analysis process included multiple readings of the case reports and attaching meaning to each case report in summary form at the end of each. It also included analysis of each category that occurred across case reports and identification of low and high level inferences from each category. Close examination of the data within each category and generation of the inferences that emerged across participants resulted in the final themes of the study. The inferences and final themes were then discussed among the researcher and two thesis advisors familiar with the data to further strengthen the confirmability of the study. Each common category as well as inferences derived is discussed to further exemplify this process. A summary of the categories derived from each participant as well as categories common across participants is provided in Table 2, Categories Across Cases.

Table 2

Categories Across Cases

Participant(s)< Category?	**Wanda & Jeff**	**Valerie, Chuck & Casey**	**Kevin, Lisa, & Chris**	**Hiedi & Michael**	**Katie & Melanie**	**Kathy & Adam**	**Courtney & Jamie**
Fears and Feelings About Impending Transition	*	*	*	*	*	*	*
Preparations for Transition	*	*	*	*	*	*	*
Importance, Role and Benefits of OT	*	*	*	*	*	*	*
Logistics of Occupational Therapy						*	*
Benefits of Inclusive OT		*					
Relationships, Feelings and Satisfaction	*	*	*	*	*	*	*
Family Involvement and Participation	*	*	*	*	*	*	*
Contact and Communication	*	*	*	*	*	*	*
Disappointments	*	*				*	

Shading indicates common categories

Fears and Feelings About Impending Transition

All of the participants shared that they experienced emotional reactions related to the transition process. Two low level inferences were derived from this category. Some parents had positive feelings and others had negative feelings regarding the transition and parents expressed very specific concerns regarding the transition such as their child riding the bus, eating, or the amount of therapy the child would receive in ECSE. One high level inference emerged from this category. Parents with children with disabilities who were most comfortable with the transition were able to see benefits of the transition and look positively toward the future for their child. In many aspects, these parents were seeking more for their children than the early intervention program could provide. In contrast, those parents who were not as comfortable with the transition or who had more negative feelings regarding the transition tended to be more comfortable with the EI services their child was receiving and were not at a point where they were looking for more. As an example, Courtney was seeking socialization, language models and respite for Jamie. Hiedi, Katie, and Kathy wanted their children to have the opportunity to be included with typically developing peers and appropriate role models. These parents had reasons for their more positive feelings about the transition process. Wanda, on the other hand, was comfortable and satisfied with the friendship, support, and therapies that she and Jeff were receiving in EI. She had no desire or reasons at that time to leave services with which she was familiar, comfortable, and content. Similarly, Valerie and Chuck were satisfied with the medical emphasis of the EI services that Casey was receiving in EI. The motivation that Hiedi, Katie, and Kathy had to have their children placed in settings with typically developing children was not an issue for Valerie and Chuck because he was already getting developmentally based services and integrated with typically developing peers in the developmental daycare that he was attending. Their contentment with the status quo resulted in less positive feelings about changing to something new. All participants shared feelings related to their child making the transition between EI and ECSE and all had concerns specific to their child, but those participants who viewed the ECSE as offering their child opportunities beyond what the EI service was able to provide them had more positive feelings about the transition process.

Preparation for Transition

Service providers assumed the primary role of preparing families for transition by providing a range of general services necessary, such as completing paper work, setting appointments, and providing information. Occupational therapists assisted families on a more specific level by providing specific activities for the children, information, emotional support, and testing. In some instances, the role of the OT in the transition was not evident to families. One high level inference that was drawn from this category was that the assistance provided from the EI staff did not address the very specific preparation concerns that parents had, such as how their children would eat, be transported, and how medical emergencies would be addressed. Although occupational therapists tended to be more attentive to specific child related concerns, this role did not occur consistently and other members of the team did not pick up this child-focused perspective. Parents were often left to their own resources to address their concerns by seeking out information and solutions, attending informative meetings, and talking to and seeking information from other parents of children with disabilities. From this information, it was inferred that parents were prepared for the general transition, however they were not prepared for specifics related to their child or the individual differences among children and families that deviated from the normal list of objectives to be met prior to the transition.

A second inference that was drawn was that the EI and ECSE perspective appeared to reflect the familiarity and comfort with these organizations that might be expected from people who work daily in the system. This comfort and familiarity appears to have contributed to situations in which service providers take the transition between the organizations somewhat for granted. Parents, on the other hand, had not seen a number of children move between systems and services, so the transition was unfamiliar to them. They remained concerned with their child's specific needs for the transition while the EI and ECSE providers were concerned with system level issues. Lack of system attention to the differences in their own perspective and those of the parents whom they serve sets the stage for parents to be discontent with the transition process.

Importance, Role and Benefits of OT

Across cases parents consider OT to be an important and integral part of the developmental program for their child, in EI and ECSE. Parents viewed the role of OT in EI as specific to the needs of their child in varying skills areas such as developmental therapies in areas of sensory integration, strengthening and adaptive skills. The role of the OT was more general in terms of benefits to parents, such as providing information, instruction, and training. In ECSE, the role of the OT remained specific to each child's needs, however most parents noted that the role of OT changed somewhat to focus more on needs related to functioning in a school environment such as writing, cutting, and fine motor skill development. The more significant the needs of the child, the less school focused services were identified. For example, Chris had very specific developmental needs. Kevin and Lisa were more concerned that he learn to eat properly and learn to walk. Skills such as writing and cutting were not really significant for them at the time of the transition. Wanda was more concerned that Jeff learn social skills for participating in a group and that he get the sensory integration therapy that he required. Other fine motor skills such as writing and coloring were not significant for her either.

By examining this category across cases, it was evident that parent’s reached a general consensus regarding the value of occupational therapy in their child’s EI and ECSE programs. Parents used such descriptors as “important,” “very, very important,” “extremely important,” and “the most important thing he gets.” The high level inference drawn from the cross-case analysis of this category was that parents viewed the role of the OT in ECSE as ever present and shifting as the needs of the child changed. OT was not viewed as a specific service that will one day no longer be needed, but rather an integral part of the EI and ECSE programs that will continually shift as the developmental level of the child changes. Occupational therapy is valued for contributing in different ways to children’s development and preparedness for school at different times in that child’s life. The transition did not change the needs of the child or the focus of the occupational therapy program, but rather the shift in emphasis changed as the child developed. For some children, this emphasis shifted toward functional skills for school. For others, the emphasis remained on needed basic developmental skills such as feeding, grasping, hand use and sensory integration skills. For example, for Jamie, Courtney described that the first year OT in ECSE focused on feeding skills and shifted to more functional “typical” OT that focused on hand skills for school related tasks. Kevin and Lisa also described this shift for Chris. OT services initially focused on basic developmental skills such as feeding and hand use. Recently, however, the focus of OT in ECSE has started to shift to skills necessary for Kindergarten placement and skills related to success in school.

Relationships, Feelings and Satisfaction

There is a diminished sense of satisfaction with occupational therapy in ECSE among parents of children with disabilities. Parents enjoyed positive relationships with the OT in EI and several parents described friendships with the OT. In contrast, there was a range of feelings regarding parent relationships with the OT in ECSE. Parents did not report the same level of friendship or partnership established in their prior relationship with the EI OT.

By examining this category, higher level inferences were discovered. One high level inference that was drawn is that satisfaction among parents regarding OT services in ECSE is closely linked to the relationship a parent shared with the therapists. Those who liked their child’s OT in ECSE and reported a positive relationship also reported more positive feelings regarding OT services in ECSE. Negative feelings regarding OT were directed more toward system level issues such as frequency of OT services. A second high level inference was that because there are fewer opportunities for parents and therapists to form a relationship in ECSE than there are in EI, OT’s in ECSE have to recognize that it is incumbent upon them to make a concerted effort to convey caring and concern to parents. The parents who met more often with their child's OT in ECSE reported more positive relationships. Those parents who transported their child to ECSE had more impromptu meetings. These impromptu meetings also helped parents to form a positive relationship with their child's OT. It was not necessary for therapists to have face-to-face interaction with parents for this positive relationship to occur. Notes home or occasional phone calls were equally effective in keeping parents informed and satisfied with OT services in ECSE.

Family Involvement and Participation

A low level inference from examination of this category revealed that parents were, as expected, more directly involved in OT in the EI program through their regular participation in OT sessions and less directly involved in OT in ECSE. Parents only occasionally observed therapy sessions while their child received services in ECSE.

Review of this category across cases revealed that few parents described being involved in the IFSP development while in EI, but nearly all parents talked about their involvement with the IEP development. A high level inference was made that active involvement in the development of the IEP seemed to serve the purpose of replacing the active hands-on involvement that parents were afforded in EI and help parents exert some control of their child's services in the ECSE program. Parents appeared to shift their level of involvement from very involved in direct occupational therapy services and less involvement in the formal planning process in the EI program, to less involvement in direct OT services to greater involvement in the planning of services in the ECSE program. A second higher level inference was made that both parental familiarity with services and the structure of the two systems influenced the change in the parents' role. Parents who are new to the provision of services for children with disabilities or developmental delays need time to learn about the system and the services before they develop sufficient familiarity to take a more active role. They tend to defer to the professionals who have expertise on disability initially and gradually become more empowered over time. EI service providers can teach parents to become contributors to their child's IFSP but the relationships that have been forged from regular contact and their involvement in the provision of services likely contributes to parents entrusting the planning process to their child's services providers. By the time that a child is transitioned to an ECSE setting parents have become familiar with the contributions of service providers and with the services that are offered by the EI system. They have a basis for comparison. Whether or not a parent assumed an active role in the IFSP planning process, by the time that they begin the IEP process, they are more knowledgeable of the planning process and better prepared to advocate for their child by making demands of the system that they feel are in their child's best interest. Greater comfort and familiarity with services and the planning process for those services coupled with being further removed from the therapy process explains why parents tended to be more involved in the IEP process than they were in the IFSP process.

Contact and Communication

Cross case analysis of this category revealed that parents were either satisfied or felt a diminished sense of satisfaction with their communication with their child's OT in ECSE compared to EI. Communication with the OT in EI was primarily verbal, occurring at each therapy session. In contrast, parent communication in ECSE was primarily written. Parents communicated with the ECSE OT using a communication notebook, written activities and progress updates. Parents were not dissatisfied that the communication was written rather than verbal, in fact they indicated a preference for written communication with their child's OT in ECSE.

Parents were also more comfortable with their means of communication with the OT in ECSE when they felt that the OT was approachable and available to them. The actual means of communication was not as important as a regular dialog with the therapist. Those parents who did not have open and ongoing communication with the ECSE OT were less satisfied overall their level of communication and felt alienated from the therapeutic process.

A high level assertion was drawn that contact and communication are linked to parental satisfaction with services, but that contact does not imply regular face-to-face meetings or telephone calls. Contact via a communication notebook that keeps parents abreast of the services that their child has received, the progress the child has made, and any recommendations for carryover at home satisfies parents' need for information and establishes a relationship between the parent and the therapist. Parents have developed an understanding that the ECSE OT cannot communicate with them verbally on a regular basis. They have accepted this as "par for the course" following the transition to ECSE. Parents do, however, expect regular written communication and to be kept informed of their child's progress in OT. When this expectation is not realized, they are left feeling alienated from the therapeutic process.

High Level Inferences

High level inferences were drawn from the cross case analysis of each category. A total of nine high level inferences resulted from the cross case analysis:

1. Parents who are most comfortable with their child's transition from EI to ECSE are able to see benefits of the transition and to look positively toward future services for their child while those parents who are not as comfortable with the transition are not yet at a point where they are looking for more.
2. Parents whose specific child-related concerns are not sufficiently addressed look outside of the system for help with the transition process.
3. Differences in perspectives of the transition process resulting from the familiarity and comfort with the process and a focus on system level issues by EI and ECSE service providers and parents' lack of familiarity with the process and a focus on specific child-related concerns leaves parents feeling that the systems lack sensitivity to their perspective.
4. Parents viewed the role of the OT in ECSE as ever present and shifting as the needs of the child changed. OT was not viewed as a specific service that will one day no longer be needed, but rather an integral part of the EI and ECSE programs that will continually shift as the developmental level of the child changes. Occupational therapy is valued for contributing in different ways to children's development and preparedness for school at different times in a child's life.
5. Satisfaction among parents regarding OT services is closely linked to the relationship a parent has with their child's therapist.

6. As there are fewer opportunities for parents and therapists to form relationships in ECSE that there are in most EI settings, it is incumbent upon OT's who work in ECSE to make a concerted effort to convey caring and concern to parents.
7. Contact and communication are closely linked to parental satisfaction with services, but that contact does not imply regular face-to-face meetings or telephone calls. Written communication is sufficient for establishing a positive relationship between the parent and the therapist.
8. Active involvement in the development of the IEP seems to serve the purpose of replacing the active hands-on involvement that parents are afforded in the EI system and help parents exert some control of their child's services in the ECSE program.
9. Both parental familiarity with services and the planning process for those services and the structure of the two systems contribute to increased parental involvement in the IEP treatment planning process.

Further analysis of these nine inferences lead to the identification of four themes. These will be discussed in the next section.

Themes

The final process of the study was theme development. As discussed above, themes were derived by a close examination of the high level inferences derived from the cross-case analysis. By combining aspects of the inferences, a total of four themes emerged allowing the researcher to draw conclusions and make assertions that were grounded in the data to answer the initial study questions.

"Seeing the Benefits of Change"

Transition from EI services to ECSE services is viewed positively when parents are able to see benefits of the change for their child and when they are oriented toward the future. Transition is a process, the process of letting go of the familiar to accept the unfamiliar (Turnbull & Turnbull, 1997). The transition process from EI services to ECSE services for parents of 2-3 year old children is unfamiliar unless they happen to have an older child with a disability and have experienced the process previously. Lack of familiarity with the new system can result in feeling uncomfortable and uncertain of what to expect, but those parents who can "see" benefits for their child as a result of changing services tend to express more positive feelings about the transition process than those parents who were comfortable with EI services and support and were not "looking for more" for their child or themselves. Benefits of ECSE services that were recognized by parents included: increased opportunities for socialization with peers, role modeling by peers, inclusion with non-disabled peers, language models, and provision of respite for the parent. Concerns that parents voiced included: loss of professional support systems, loss of involvement in the therapy process, their child's medical fragility/medical procedures, and perceptions by parents that their child had not reached a developmental level to benefit from peer socialization.

As stated by Rosenkoetter et al. (1994), transitions can be both satisfying and enabling for children and their families, however this process can also be a source of stress and present challenges. These conflicting positive and negative feelings described by participants in the current study are consistent with the family life cycle literature (Turnbull & Turnbull, 1997) which considers all transitions as stress points for families.

Transitions have three phases. In the first phase, families must let go (i.e., grieve the loss of something). In the middle phase, families are unsure of where they stand; they no longer have the old situation, but are not yet comfortable with their new situation. In the last phase, families are able to accept and celebrate the new. This process may best explain the conflicting positive and negative feelings described by families as each family may have experienced each phase at different times. Some parents, especially Wanda, may not have reached the final phase at the time of this study. The family life literature exemplifies the role of the professional in assisting families during the transition by providing information and guidance. As Kathy astutely stated: "[When] you have a child with a disability, there is no guidebook, there is no one there to help you along, so you are counting on a lot of professionals to turn you in the right direction."

The current findings are similar to those found by Hanson et al. (2000). In the theme described as “impact of shifting systems on families and children,” anxiety by parents was expressed concerning moving from one system to another and was often described with a sense of dread. Also similar to the findings by Hanson et al., parents expressed concern of the child’s readiness to participate in preschool and especially inclusive preschool.

“*Differing Perspectives of Transition”*

Parents viewed the EI and ECSE systems as not sharing their same perspective on their child's transition. Parents considered that the EI and ECSE systems viewed the transition of their child from a broad perspective, taking a more generic view of the transition between their systems. Their view is like that of a wide-angle lens in contrast to the parents' much more specific, child-focused "up-close and personal" view that more closely resembles the perspective of a close-up or "telephoto" lens. They are both focused on the same event but the views are quite different. Parents view the EI and ECSE systems as focused on systems-level issues while their own focus tends to be very child-specific. The details that concern them often go unaddressed by the systems that were set up with the intention of helping them, forcing them to look outside of the system such as to other parents of children who have made the transition previously.

Families expressed very specific concerns regarding the transition of their child to the ECSE program. Concerns the parents expressed included safe transportation, medical emergencies, knowing in advance who would service their child, and very child specific feeding issues. Parent's needed answers and solutions to their specific questions and concerns to feel comfortable, secure, and look forward to the transition. The family perspective of the transition was very child focused. In contrast, the perspective of the EI and ECSE teams was focused on system level issues such as paperwork, referrals, records transfer, scheduling visits to new schools, and attending eligibility and IEP meetings. Families were left feeling lost and uncertain, and to find answers and solutions to problems on their own. They were left to develop their own support networks and wonder how their concerns would be resolved. It seems that the transition process "lost" the very family-centeredness so crucial to early intervention services. One family very eloquently expressed their feelings of preparation. As Kevin and Lisa stated: "We were pretty much accepting and pretty adjusted to it [transition] or else we would have just kept him in early intervention for one more year. What we weren't prepared for though…[was] going into a public school system." These findings are consistent with those by Filer and Mahoney (1996) whose findings concluded that there is a lack of correlation between the views of families and professionals and contributed the lack of correlation, in part, to the difficulty that some professionals may have in describing what services they provide. In addition, the authors in this study concluded that limited conversation pertaining to the services that are actually taking place or that an unsystematic approach to working with families might also contribute to a lack of correlation.

Findings of the current study are also consistent with those found by Hanson et al. (2000) in that the transition was viewed as an event not a process, and preparation was targeted toward that very specific event. In this study, parents and professionals alike saw the transition as a specific event or meeting rather than an extensive process of planning for the child and family. These findings are also similar to those found by Filer and Mahoney (1996) that described a lack of correlation between the services that families reported receiving and those services providers reported delivering in the areas of child information, system engagement and resource assistance.

"*The Dynamic Role of the Occupational Therapist*"

The role of the occupational therapist is viewed as dynamic, shifting in response to the needs of the child, the family, and the system. Parents viewed the occupational therapist as equally important in both the EI and the ECSE programs. Benefits of the services of the occupational therapist in EI were evident to parents for both the child, in developing needed skills, and for the parent, in helping them to adjust to their child's disability as well as providing them techniques to assist their child in the developmental process. Parents viewed the role of the occupational therapist as shifting in response to the needs of their child in that as the child developed needed skills, the therapist continued to challenge their child with activities requiring increasingly higher levels of independence and functioning. This included directing attention to goals beyond the family and home environment such as developing the skills necessary to be successful in the ECSE classroom environment. For Wanda, the OT continued the therapy initiated in EI but shifted to incorporate needed sensory integration therapy to help Jeff become a successful learner in the ECSE preschool classroom. For Valerie and Chuck, the OT moved from developmental therapy in the developmental daycare setting to higher-level school related tasks such as writing and cutting skills. For them, the OT was a key player in integrating Casey into the classroom with non-disabled peers.

Others described the OT as providing direct one-on-one therapy in EI, yet viewed her role as shifting to therapy in the larger classroom context in ECSE. In this larger context, the OT considered the needs of the family, the teacher, and the other students as well. Parents described efforts the OT made in considering the child's skills that the family can follow through at home and often provided brief therapy notes or other activities to incorporate in the home routine. The parent's also described ways that the OT shifted direction of services to meet the needs of the teacher and other students in the classroom. Some parents considered that the OT was able to assist the child by modeling techniques for the teacher so that she was able to carry those techniques over throughout the child's day; while others described that the OT was able to demonstrate to the other student's ways that they could become involved in helping and including the child with disabilities in the classroom. One mother described this shift in response to the developmental needs of her child. In both EI and ECSE, the parent viewed OT as working on specific developmental milestones and then beginning to shift services toward specific school related tasks. As Lisa explained: "It's tending to shift some now, I mean, they're not so much doing the basics as they were earlier because he's met those milestones." Courtney also recognized a shift in OT services for Jamie. She described how in EI the primary role of the OT was feeding and respite for her. In ECSE, the OT initially worked on feeding, almost exclusively. She then recognized a shift in the focus of OT in ECSE: "Now that has changed…now the OT is actually working on her fine motor and adaptive skills. Now we're going into a new page with OT where she will be getting more typical…OT services."

The literature describes the shift in emphasis from family-centered to child-centered services in the transition (Blasco, 2001). However the current study expands this shift to describe the shift in the role of the occupational therapist. The role of the occupational therapist shifts to meet the needs of the child and system, and to a lesser extent to meet the needs of the family as the child transitions to the ECSE environment. Different from other professions, however, the occupational therapist was credited with maintaining some aspect of the family focus following the transition to the new ECSE classroom environment. While the role of the OT has changed to meet the specific needs of the child in the new environment, the needs of the family were also considered in most instances. As Wanda so eloquently stated: "I had that really committed, like overzealous OT, who [made me feel] like I was still in the infant program…she spoiled me."

"Communication, Involvement, and Relationships are Intimately Related"

The level of communication that exists between the parent and the occupational therapist defines their relationship. Parents often miss the positive relationships, involvement, and communication between themselves and their child's OT in EI. Occupational therapists can help in small ways by recognizing that parents want to know about their child's therapy and progress by providing frequent therapy updates or quick notes about how their child performed during the therapy session in ECSE.

Families often expressed that they would like more communication with the occupational therapist in ECSE. They were not as concerned with the means of communication as they were with the frequency of communication and the availability of the therapist. Parents wanted to know how their children were doing in therapy and things they could do at home to facilitate therapy goals. Parents realized that they could not maintain the same level of involvement as they once had while their child was in EI and therefore communication with the OT became much more important to them. Some families described ongoing communication through impromptu meetings with the occupational therapist when picking up their child from ECSE preschool. Others described regular team meetings or regular notes in a communication notebook, while others described communication during or after observation of treatment sessions. These open lines of communication helped them to feel connected to the therapy process despite not being as involved, as they once were when their child received EI services. These families also described more positive relationships with the occupational therapist in ECSE because they had a sense of who the therapist was and that their child was important to her. As one mother said: "I'm not there all day so I don't know what he does…but I still need to know what he did so we can talk about it and keep it going at home." Those parents who did not feel that they had an open dialog or ongoing communication with the ECSE OT were less satisfied overall with their level of communication and felt alienated from the therapeutic process. One mother expressed heartfelt disappointment with the level of communication with the OT in ECSE: "I don't hear from her [OT]; she doesn't let me know what's going on or anything like that…I don't see her regularly or hear from her regularly. There's just not enough…I think there should be more communication."

Parents had a difficult time separating communication and involvement from the relationship that they shared with the occupational therapist, particularly in ECSE. When asked to describe their relationship, parents frequently responded first by describing their level and means of communication and involvement. They frequently required prompting to describe their feelings about and relationship with the OT. This difficulty in separating communication and involvement from relationship helps to explain and express the extreme importance of open communication for families and therapists alike. For these families, communication was the key to establishing positive relationships and feeling involved in the therapeutic process. As one mother explained, "There's not as much communication just because we [don't see them] as often. We don't get many notes in the notebook unless we specifically ask. And this one [current OT] I think Kevin's more, has more of a relationship with than I do because I've only ever seen her once; I didn't even know what she looked like until a couple of months ago. I've met her once [and Kevin] met her twice."

McWilliam et al. (1995) reported findings that convey this same sentiment regarding professional support. Their findings revealed that families reported overwhelmingly high satisfaction with early intervention programs, and in-depth interviews revealed that the source of much satisfaction was the personal support provided by individual professionals. In this study, parents described more satisfaction when professionals portrayed a caring demeanor toward working with their children. Although findings in the current study consider parental communication with occupational therapy specifically, these findings are similar to the findings in the aforementioned study of families' needs by Pruitt et al. (1998). In this study, parents indicated wanting educators to listen to them, respect their contributions, and listen to their personal issues in addition to having a desire to improve the quality and quantity of communication. Parents indicated a desire to be listened to, to establish effective communication with professionals, and to work with professional who demonstrate sensitivity and respect for their children. Hanson et al. identified a similar theme in their 2002 study exemplifying the importance of information exchange and communication. Their findings indicated a strong desire of parents to be heard and to participate in the transition process as well as a crucial need for information exchange between systems and service providers prior to the transition.

The degree of parental involvement in the provision of treatment was also intimately related to the relationship the parent shared with the OT, however the involvement the parent shared changed following the transition. While a child and family participated in EI, the parent was intimately involved in the therapeutic process, engaged along with the child and therapist. Interestingly, while involvement of the parent in treatment was high in EI, the extent of involvement of the parent in the IFSP development was less prominent. This level of involvement inversely changed from active participation and involvement in occupational therapy treatment to less active participation in occupational therapy treatment but much more active involvement in development of the IEP. Few parents described being involved in the IFSP development while receiving EI services. This decreased involvement may be due to unfamiliarity on the part of the parent with the system, but also because they were in many cases, physically present and observing services or had others (i.e., daycare workers) who were able to keep them informed on a daily basis. Regular direct or indirect monitoring of services kept them informed of current goals and progress. In comparison, all parents described or implied involvement with the development of the IEP once the child transitioned to ECSE. This may be explained by the increased familiarity of parents with the system and process of service provision for children with disabilities, but in this study the increased interest in involvement of their child's treatment plan was linked to the need to maintain a level of involvement when a change in systems results in parents no longer being around to "monitor" their child's therapy on a regular basis. The IEP may be the only way that parents feel involved with or have control over their child's services in the ECSE program. As Courtney explained, "I was in a state of despairs…I didn't [help with the IFSP development]…they did it, pretty much and I said OK." She further explained, "I think an IEP should be looked at every month…if you, as a parent, are on top of things, that's when you get action. When the parents get more involved and are more verbal about it, then they [ECSE staff] will focus more and they'll be more goal oriented if you are present." These findings substantiate the findings by Plunge and Kratochwill (1995) that parents report the greatest level of involvement in the child's special education services in parent comments during the IEP meeting regarding their child's strengths and weaknesses as well as signing the IEP. This study did not address the findings of the current study regarding the inverse relationship of parental involvement from that experienced in EI to that experienced in ECSE.

The current study more closely examined the desires of parents to maintain an ongoing communicative relationship with their child's occupational therapist in order to carry over necessary skills at home and feel involved and an active part of the therapeutic process with their child. It also exemplifies that occupational therapists working with children and families in ECSE must put forth greater effort to involve parents in the therapy process by projecting a caring demeanor toward working with children, a demeanor that could easily be conveyed through ongoing contact with the parent via brief notes or other written communication on a regular basis.

Tables 3 and 4, Themes and Supporting Quotations, list the four themes and the quotations that help to support the assertion that themes are grounded in the raw data.

Themes in Relation to Study Questions

In summary, four themes emerged from the data and inferences generated during this investigation. These themes help to answer the research questions posed in the beginning of this chapter, specifically:

1. How do parents of children who formerly received early intervention services and who currently receive early childhood special education services view the role and benefits of occupational therapy in their child's preschool program?

Table 3

Themes and Supporting Quotations

Themes	Supporting Quotations
Theme 1. "Seeing the Benefits of Change" Transition from EI services to ECSE services is viewed positively when parents are able to see benefits of the change for their child and when they are oriented toward the future. Parents who can "see" benefits for their child were more positive about the transition. In contrast, parents who were comfortable with EI and not "looking for more" had a harder time with the transition.	● "She needs to go, move on. For the socialization...just the variety...she's so social and so verbal she had people to talk to and...she was gonna get a fuller four hours. I was excited. I so much needed that break." ● "We weren't really wanting to do it [transition] anyway because we thought he was getting quite good care where he was at. We didn't think he was ready and we weren't ready for him to go to school." ● "At first I didn't want to leave it [EI program] because I was comfortable with it…it's daunting…it's "scary" when you move, leaving something familiar to go someplace new…it takes a few times for that to "soak in" because it's all a foreign, the whole procedure is not known to newcomers to this "club" of disabilities.
Theme 2. "Differing Perspectives of Transition" Parents viewed the EI and ECSE systems as not sharing their same perspective on their child's transition. Details that were concerning to families were left unaddressed by the systems set up to serve them, leaving families to find solutions and answers on their own.	● "He couldn't feed himself at the time, I'm like "Oh my God, how's he gonna eat at lunch time? Are they gonna feed him? What are they gonna do?"...They didn't tell us that in the preschool program they stay in their classroom for lunch." ● "[Getting] parent's involvement or help was really nice...but if I hadn't known anybody, I would have been 'up the creek.' I would have probably just taken him to the regular [public school] because that's what they...tend to encourage you to [do]. ● " I didn't think to ask it [regarding therapies]…so many things I didn't even think to ask." ● "I think a lot of times as parents you assume that since it was that way at another place, it's gonna be that way at this place...I think it's a collaborative effort on a lot of people's part because there are a lot of questions that parents have and a lot of rights that parents don't know that they have. It's a difficult transition to go from one thing to the next thing…you're going to different levels." ● "As parents and you have a child with a disability, there is no guidebook, there is no one there to help you along, so you are counting on a lot of professionals to turn you in the right direction."

Table 4

Themes and Supporting Quotations

Themes	Supporting Quotations
Theme 3. “The Dynamic Role of the Occupational Therapist” The role of the occupational therapist is viewed as dynamic, shifting in response to the needs of the child, the family, and the system. Parents viewed the role of the occupational therapist as shifting in response to the needs of their child in that as the child developed needed skills, the therapist continued to challenge their child with activities requiring increasingly higher levels of independence and functioning. This included directing attention to goals beyond the family and home environment such as developing the skills necessary to be successful in the ECSE classroom environment.	● “It’s tending to shift some now, I mean, they’re not so much doing the basics as they were earlier because he’s met those milestones.” ● “Now that has changed...now the OT is actually working on her fine motor and adaptive skills. Now we’re going into a new page with OT where she will be getting more typical...OT services.” ● “…They took their work very seriously and it wasn’t just work to them, it was personal.” ● “I look at it [OT] more as a…parental training as opposed to “fix[ing]” my daughter.”
Theme 4. “Communication, Involvement, and Relationships are Intimately Related” The level of communication that exists between the parent and the occupational therapist defines their relationship. Parents often miss the positive relationships, involvement, and communication between themselves and their child’s OT in EI. Communication is the key to establishing positive relationships with OT and feeling involved in the therapeutic process. The means of communication was not as important as the frequency of communication for parents. Those parents who did not have an open line of communication with OT felt alienated from the therapy process.	● “I think she was a rare breed...I felt like I knew here and felt like I could approach her so much more than any of the one’s I’ve had since then...she spoiled me...I would get a note from her every time she saw him and that was wonderful...she would write in his communication book.” ● “There’s not as much communication just because we [don’t see them] as often. We don’t get many notes in the notebook unless we specifically ask.” ● “I don’t hear from her [OT]; she doesn’t let me know what’s going on or anything like that...I don’t see her regularly or hear from her regularly. There’s just not enough...I think there should be more communication.” ● “I like to know who’s working with my kid and what kind of personality they have and if “they’re clicking” because if they’re not clicking it’s not going to be ideal for anybody to learn.” ● “I would get a note from her every time she saw him and that was wonderful…she would write in his communication book…something that apparently no one else does…it’s never happened since.” ● “She [OT] communicates to me how he’s doing in her area. I appreciate having something in writing…I need that.” ● “I think it’s the way that the OT, Speech, and PT people approach you and how comfortable they make you feel and how much the little extra they’re willing to go to help benefit your family.”

This research question was answered with in the discussion of theme number three, the dynamic role of the occupational therapist. Parents viewed the role of the occupational therapist as equally important in both programs and that role was seen by parents as dynamic, and quite capable of shifting in response to the needs of the child, the family and the system. These needs often shifted beyond the family and home in EI to the broader environment of the school and ECSE classroom.

2. How do parents conceptualize the differences between service delivery of occupational therapy in early intervention and early childhood special education? Theme number three, the dynamic role of the occupational therapist, also addressed this research question. Parents viewed the occupational therapist as directing attention to goals beyond the family and home environment to skills necessary to be successful in the ECSE classroom environment. For Wanda and Jeff, the OT incorporated needed sensory integration therapy to help Jeff become a successful learner in the ECSE preschool classroom. For Valerie, Chuck and Casey, the OT incorporated higher-level school related tasks necessary to integrate Casey into the classroom with non-disabled peers. Parents also described the OT shifting from a predominantly developmental focus in EI to the larger classroom context in ECSE. While still attending to the needs of the family, the teacher and the other students in the classroom became increasingly important. The OT often modeled techniques for the teacher to implement during the school day and involved the other students in skill areas.

3. How do parents describe the type and extent of communication with their child's occupational therapist as school? How has this changed from that of early intervention? How do parents describe the effectiveness and their level of satisfaction with this communication in comparison to the effectiveness and satisfaction with the communication they had with their child's OT in early intervention? Theme number four, communication, involvement, and relationships are intimately related, specifically addressed this research question. Families expressed that they would like more communication with the occupational therapist in ECSE. They were not as concerned with the means of communication as they were with the frequency of communication and the availability of the therapist. Communication occurred in a variety of ways in ECSE, such as through written communication book, impromptu meetings and scheduled meetings. In contrast, communication with the OT in EI was primarily verbal for families, occurring before, during and after treatment sessions. Those families who had an open line of communication with their child's OT in ECSE reported positive relationships. In contrast, those who did not have an open line of communication felt alienated from the therapeutic process. Satisfaction with the OT services that their child received was closely tied to the quality of the relationship between the parents and the therapist.
4. How do parents describe the type and extent of their involvement with their child's occupational therapist at school? How has this changed from that of early intervention? Theme number four, communication, involvement, and

relationships are intimately related, also answers this research question. The degree of parental involvement in the provision of treatment was intimately related to the relationship the parent shared with the OT, however the involvement the parent shared changed following the transition. While in EI, the parent was intimately involved in the therapeutic process, engaged along with the child and therapist. Parents described much less involvement in OT in ECSE. Involvement was limited to occasional observation of treatment sessions. However, this research revealed that involvement inversely changes from a high level of involvement in treatment and less involvement in IFSP planning in EI, to a low level of involvement in treatment and a high level of involvement in IEP planning in ECSE. The means for involvement in their child's development and therapy changes in part because of the difference in systems.

5. In what ways can occupational therapists help make the transition process flow smoothly for parents and children transitioning from early intervention to early childhood special education? Theme number one, seeing the benefits of change, and theme number two, differing perspectives of transition, help to answer this research question. Parents expressed positive feelings about the transition when they were able to see the benefits of the transition for their child. Those who were not looking for more in terms of services of their child, or who were not able to see benefits of the transition viewed the transition more negatively. Theme number one identified the areas of need for parents in the transition process, such as the need for assistance in

> identifying benefits of the transition for the family and the child as well as providing support, information, and guidance. In theme number two, parents expressed very child specific concerns regarding the transition of their child to the ECSE program. Parents' needed answers and solutions to their specific questions and concerns to feel comfortable, secure, and look forward to the transition. This theme helped to highlight the role of the occupational therapist in assisting families in finding answers and solutions to their child specific questions and concerns. By assessing the family and the child in relation to the transition, the occupational therapist can provide much needed services in this area.

Parents who were able to envision benefits of the transition and who were oriented toward the future had a more positive view of the transition. Parents viewed the EI and ECSE systems as not sharing their same perspective on their child's transition. The parents viewed the transition from a very child-specific perspective, and voiced concerns very specific to their child and family needs. In contrast, EI and ECSE personnel appeared to view the transition from the system perspective, concentrating their efforts on system level issues such as completing paperwork, scheduling meetings and visits, and records transfers. This differing view of the transition left parents feeling lost and uncertain, and to find answers to solutions to problems on their own, as well as to develop their own systems of support. Despite the change in setting from EI to the ECSE classroom, parents often missed the positive relationships, involvement and communication between themselves and their child's OT that they shared in EI. Communication, involvement, and relationships were intimately related. The level of communication that existed between the parent and OT defined their relationship and the frequency of communication became increasingly important as active involvement in the therapy process diminished for the parent following the transition. This diminished involvement in the therapy process appears to have contributed to the change in level of involvement in the treatment planning process with parents assuming more active involvement in the IEP process when the child makes the transition to ECSE services. For these parents, involvement in the IEP development kept them involved and in control of their child's services.

Limitations of the Study

It is important to understand the limitations of this study. The reader should consider that the purpose of this study was to describe the perceptions of parents of occupational therapy services in early childhood special education programs following transition from early intervention programs, and how these perceptions have changed over time from the perspective of the seven families of children with disabilities who participated. While every effort was made to select families that represented this population in general, variables among participants did not always lend themselves well to generalizations. The seven participants had children with varying disabilities ranging from mild to severe, thus varying their experiences and approach to the transition. Participants were not all given the same programming options during the transition, and participants varied in their level of education, economic status, and acceptance of their child's disability.

I approached this study with an implicit bias toward the families receiving services and participating in this study because of my profession as an occupational therapist and work experience evaluating and treating children in an early childhood special education program. In addition, I have experienced such a transition many years earlier along with my son with disabilities. However, qualitative research methods include strategies to lessen the effects of such biases and preconceived assumptions (Patton, 2002). I incorporated several of these methods in this study to guard against these biases such as: recording detailed fieldnotes that included personal reflections regarding my subjectivity, peer debriefing to "check" my interpretations with a unbiased third party, member checking to confirm and compare my interpretations and impressions with the family participants, and a thorough external audit.

Implications

Implications for Future Research

This study explored issues related to the transition process for families transitioning from early intervention to early childhood special education in southeastern Virginia. More research will be needed for the profession of occupational therapy to fully meet the needs of children and their families during this time of change. Specifically, research addressing the transition between systems, particularly in Virginia, would be helpful in assessing the ability of systems to adequately meet the child-specific needs of the families they serve. In addition, research geared toward specific aspects of the transition process such as professional responsibility and role delineation of service providers would be beneficial to professionals and the families they serve. One interesting finding was that parents often looked outside of the system for assistance in the transition, such as from other families whose children previously transitioned. Professional systems cannot be expected to fulfill the need for this kind of information in the same way that can be provided by someone who has experienced the process personally. The compassion, empathy, and understanding of having “been there” can provide invaluable guidance for parents anticipating or just starting the process. However, it could be useful for therapists to know the kinds of advice and information that previously transitioned families tend to share and the benefits of that advice and information to newly transition families in making the transition process easier. This information may be generalized and routinely shared by service providers and other professionals working with families.

Research that investigates the occupational therapy perspective of the transition process would also be beneficial to the profession. A sound research design that investigates the occupational therapist’s perspective on the role of the OT, communication and involvement with families, and the tasks in which the OT engages in order to prepare the family for the transition would be beneficial for the profession. Additionally, an investigation into the preparation that OT’s practicing in EI and ECSE received during their entry-level education and through continuing education would be beneficial in determining the preparation that OT’s feel that they need in order to practice competently in these two areas.

Implications for Practice

Several factors that influence the profession of occupational therapy and other professions that work with this population of children became evident from this inquiry. The first is the lack of clear delineation of the role of the occupational therapist in the transition process, in maintaining the family-centered care perspective once the child transitions to the ECSE program, and in maintaining open lines of communication with families once the transition is complete. Additionally, the role of the occupational therapist in evaluating the transition for the child and family could be expanded, or at least clarified, regarding the expectations and outcomes from both an entry-level education perspective and from the perspective of the practicing therapist in both early intervention and early childhood education. These implications for practice will be examined as they relate to the final themes of the study as well as in relation to entry-level education, early intervention practice, and early childhood special education practice perspectives. These are summarized in Tables 5 and 6, Implications for Practice.

The first theme of this study, “Seeing the Benefits of Change” highlights the importance of maintaining a positive view of the transition for parents. Entry-level educators can expose students to the family-centered care philosophy during instructional activities emphasizing the positive benefits of early intervention and early childhood special education programs. Further, OT students in entry-level programs can engage in activities that examine the transition from differing perspectives such as that of the family, the EI therapist, and the ECSE therapist. This multi-faceted examination would help students to “see” the benefits of each treatment environment from the perspective of differing individuals at different phases in the transition process.

Occupational therapists providing services to families in the early intervention program can help parents in this phase of the transition by providing information that helps them to “see” the benefits of ECSE. Therapists can point out the positive aspects of ECSE such as socialization with an appropriate peer group, inclusion with children

Table 5

Implications for Practice

Theme	Implications for Entry-Level Education	Implications for Practicing EI Therapists	Implications for Practicing ECSE Therapists
"Seeing the Benefits of Change"	•Expose students to family-centered care philosophy, highlighting benefits of each aspect of care •Provide opportunities for students to examine the transition from the EI and the ECSE perspective	•Provide information to parents to help them "see" the benefits of ECSE •Point out positive aspects of ECSE: i.e., socialization, inclusion, respite •Be aware of the influence that therapists have on parents and potential to make transition positive •Be prepared to "let go" so that families can move on •Be aware of potential for unintentional sabotage	•Incorporate brief orientation for parents during initial evaluation •Explain positive aspects of ECSE and inclusive therapy •Encourage parents to visit ECSE classroom and "new" therapist prior to the transition •Lessen the parents apprehension by giving them "permission" to visit the ECSE program
"Differing Perspectives of Transition"	•Expose students to family-centered care philosophy, highlighting benefits of each aspect of care •Provide opportunities for students to examine the transition from the perspective of the parents and the professionals •Help students to relate aspects of family-centered care and different perspectives to real practice situations	•Maintain family-centered care perspective throughout transition •Listen, support, and provide information specific to child and family •Pursue continuing education regarding family-centered care and family systems •Review the OT Code of Ethics and Core Values and Attitudes of OT Practice •Prepare for transition for each child and family specifically	•Maintain family centered care throughout transition, when making initial contact with family (i.e., initial evaluation) •Recognize critical window of opportunity to establish a positive relationship with the family •Explain that change in environment may necessitate shift in treatment approach •Obtain knowledge of the documents of the profession •Prepare for transition for each child and family specifically

Table 6

Implications for Practice

Theme	Implications for Entry-Level Education	Implications for Practicing EI Therapists	Implications for Practicing ECSE Therapists
“The Dynamic Role of the Occupational Therapist”	•Articulate need for role clarity for students •Familiarize students with documents of the profession •Compare and contrast treatment focus and intervention for different systems •Provide opportunities for students to articulate the role of OT to different recipients of service	•Clearly describe therapeutic techniques utilized and therapeutic reasoning leading to shifts in treatment •Explain to parents the importance of considering the child’s environment when developing plan of care •Conduct joint evaluation of the transition with ECSE OT	•Describe techniques utilized and therapeutic reasoning leading to shifts in treatment •Explain the importance of considering the child’s environment in treatment •Conduct joint evaluation of the transition with EI OT considering environmental, child, and family factors as well as supports, skills and preparation needed in ECSE
“Communication, Involvement, and Relationships are Intimately Related”	•Expose students to communication techniques, communication styles, styles of learning •Elaborate on need for frequent and ongoing communication with families in EI and ECSE	•Assess family’s preferred style of communicating, learning, and frequency of communication •Maintain ongoing and open lines of communication with families •Prepare families by helping them to gain skills necessary for efficient, effective, and satisfying communication both in EI and ECSE.	•Exhaust all efforts to make initial contact with families early in transition process. •Determine family’s preferred style of communication and learning, and preferred frequency of communication •Establish and maintain ongoing, open communication with families early in the relationship-the sooner the better.

who are developing normally, and the benefits of respite for parents. It is also important for therapists practicing in early intervention to be aware of the incredible influence they have on parents and the potential that they hold in helping parents prepare for a positive transition. Often early intervention therapists provide their services in the child’s home, providing them with an ideal context for relationship building with the family. ECSE therapists work predominantly in center-based sites, which do not allow for the level of family contact to which the family has grown accustomed. Family-centered care is still possible to accomplish in ECSE, but the change in setting from home to school makes it slightly more challenging to achieve. As professionals, EI OT’s must be acutely aware of when it is time to “let go” in order to allow families to build a rich and rewarding therapeutic relationship with the next occupational therapist in their child’s life, the ECSE OT. By failing to let go of these relationships and by failing to positively and adequately prepare parents for the difference in treatment environments, EI therapist may be unintentionally sabotaging the efforts of the ECSE therapist to build a strong therapeutic relationship with families.

Occupational therapists practicing in ECSE also have an important role in helping parents to see the benefits of the transition to ECSE. OT’s are often tasked with conducting an initial evaluation during the transition process. ECSE therapists can incorporate a brief orientation for parents during this time to explain how therapy in the ECSE program might be conducted, where it will occur, and also to emphasize the positive aspects of inclusive therapy. ECSE therapists can also encourage parents to visit the ECSE classroom and introduce themselves to the therapists who typically practice in that setting. By giving parents "permission" to visit, their apprehension will be lessened.

The second theme, "Differing Perspectives of Transition" exemplifies the need for occupational therapists to maintain the family-centered care perspective before, during and after the transition. This inquiry revealed a need for clear role delineation and specific education for occupational therapists regarding family-centered care. In many instances, families had a difficult time describing the role of the occupational therapist. This leads one to wonder the extent that occupational therapists are prepared for working with families of children with disabilities in their entry-level education and how information about the profession and the role that OT's play in EI and ECSE services is disseminated to families. For educators in entry-level programs, using the suggestions in "Seeing the Benefits of Change" would allow students to experience the transition from differing perspectives and encourage them to be family-centered as they encounter these opportunities in practice.

Occupational therapists practicing in EI can maintain the family-centered care perspective throughout this process by listening, supporting and providing information for parents that addresses specific child and family level concerns throughout the transition process. Occupational therapists practicing in EI are in a unique position due to the positive relationship that they have previously established with the family to understand each family's unique perspective in relation to the transition. Families will be more likely to confide in professionals with whom they have established trusting relationships. Additionally, therapists in EI have the responsibility to maintain ongoing continuing education in the area of family-centered care and family systems to best support families during the transition and to meet the challenges of working with varying family dynamics.

Therapists practicing in ECSE can also maintain the family-centered care perspective throughout the transition process, but especially when making the initial contact with the family for the initial evaluation or visit. The onus is on ECSE OT's to recognize the critical window of opportunity that exists at the time when a child transitions to ECSE to establish a positive relationship with the families as well as with the children they serve. The ECSE therapist can take this time to explain how shifts in a child's environment can necessitate a shift in treatment approach. By maintaining the family-centered care perspective, ECSE therapists must understand the level of services a family has become accustomed to in EI in order to create a positive environment for the child and subsequently a positive transition for the family. Knowledge of the documents of the profession such as the Occupational Therapy Practice Framework: Domain and Process (AOTA, 2002), the Occupational Therapy Code of Ethics (AOTA, 2000), the Standards of Practice for Occupational Therapy (AOTA, 1998), and the Core Values and Attitudes of OT Practice (AOTA, 1993) can assist therapists in bridging these services for children and their families. Preparation should be geared toward the very specific needs of each child and family in anticipation of the transition and beyond, closely adhering to the already established principles of best practice for the profession in helping clients orient toward the future and maintaining the family-centered perspective (Dunn, 2000).

"The Dynamic Role of the Occupational Therapist," the third theme that emerged from the study, examined the parents' perspective of the role of the occupational therapist but also revealed that parents had a difficult time describing the role that the OT played in the transition. The need for research regarding the role of occupational therapy in the transition process is crucial to providing quality services for children and their families and for increased confidence in sharing the uniqueness of the OT perspective with families. However, we should not wait for this research to be conducted to begin utilizing common sense strategies in our role as providers of family-centered care. Entry-level educators can play a large part in the area. By clearly articulating to students the need for clarity in presenting our role to families, OT's and educators can take the first steps in clearly defining for families the responsibilities of the OT. Additionally, by familiarizing students with the documents of the profession, educators can ensure that professional standards are adhered to when students enter the professional level and begin working with families and children with disabilities.

Occupational therapists practicing in EI have a responsibility to describe to parents various treatment techniques as well as shifts in treatment approaches. Providing parents with the therapeutic reasoning will ensure that they are informed of the unique skills occupational therapists bring to the evaluation, treatment, and transition process. These "shifts" in treatment focus are important in the treatment process and it is equally important to inform families of the reasons for these shifts. Changes in environment often bring about changes in treatment.

Therapists practicing in both EI and ECSE can take the initiative of conducting a joint evaluation of the transition process. These therapists are in a unique position to assess what supports exist in the current environment, and what will need to be established or obtained prior to receiving the child in order to meet the needs of the child in the next environment. Additionally, by looking toward the next environment, the EI and ECSE occupational therapists can jointly determine the preparation necessary and the skills needed by the child to be successful.   By informing and explaining these shifts to parents before, during, and after the transition, a seamless transition will most assuredly follow.

Occupational therapists, by virtue of their ability to assess all aspects of an environment, can best address these specific individual, child-level concerns by evaluating the transition not only for the child with disabilities, but for the entire family. An evaluation of the transition itself would clearly determine support set up to meet the needs of the child and family as well as identify those supports necessary for a seamless transition for that particular family. A joint evaluation of the transition conducted by the sending and receiving therapist (i.e., EI and ECSE therapist) can reveal very valuable information regarding the perspective of the family and offer an opportunity for therapist to share crucial treatment information. By assessing environmental factors, child factors, and family factors, occupational therapists can influence the success of the child in the next environment

This inquiry appears to indicate a need for increased training for occupational therapists working with these populations and assisting families in the transition from EI to ECSE programs. Due to the varied options that parents were offered during the transition, it appears the training could best be accomplished at the system level. EI and ECSE programs could best prepare occupational therapists in working with families at their system level. Theories of family systems and principles family-centered care could also be offered as continuing education for occupational therapists and other professions working with families of children with disabilities. In light of recent continuing education requirements by the National Board for Certification in Occupational Therapy [NBCOT], this level of continuing education would likely be welcomed by therapists working in these areas.

The final theme, "Communication, Involvement, and Relationships are Intimately Related" addresses the crucial need for ongoing open lines of communication between the therapist and the family in forming positive therapeutic relationships for the therapist, child, and family. Turnbull & Turnbull (1997) clearly articulate the need for communication when professionals work with families of children with disabilities and the current study substantiates this related to the more specific needs of families to communicate with their child's occupational therapist. The entry-level student can be exposed to communication techniques when working with families, such as family styles of communication, styles of learning, and communication techniques such as verbal, written, and a combination of these methods. Educators teaching entry-level students can help by training occupational therapists who understand the need of frequent and ongoing communication with families in EI and ECSE.

The impetus to establish line of communication with the family is on the treating therapist. He or she should discuss with families their preferred form of communication by assessing their family situation, their learning style, and determining the means and frequency of communication they are most comfortable with. Occupational therapists in both the EI and ECSE programs can assist families in determining their preferred level of communication as well as determining frequencies of communication that will work for the entire team. Ongoing communication can be established in a variety of ways, including daily or weekly communication notebooks, impromptu meetings, formal meetings, or occasional or regularly scheduled telephone calls. Early intervention staff can prepare families by explaining that communication, involvement, and relationships are “two-way” and by helping them to gain the skills necessary for efficient, effective and satisfying communication and involvement in the therapy process.

Therapists working with families in ECSE, especially those therapists who make the initial contact with families are in a unique position to take advantage of the critical window of opportunity to establish a positive relationship with families whose children are entering the ECSE program for the first time. It is imperative that ECSE therapists exhaust all efforts to make the initial contact with families in this critical stage of the transition. Therapists should try to gain an idea of the family’s perspective and make an effort to determine the family’s preferred means and frequency of communication. It is the responsibility of the treating therapist to maintain open lines of communication and to make a concerted effort to establish this initial contact. This initial effort will go a long way in establishing a rewarding therapeutic relationship for the therapist, family and ultimately the child as well as establish a means of keeping families involved in the therapeutic process.

As summarized in Tables 5 and 6, occupational therapists, including educators in entry-level occupational therapy programs and therapists practicing in early intervention and early childhood special education programs, all have the responsibility of encouraging or providing assistance to families at all levels of the transition process. The onus is on us to maintain a professional level of responsibility that includes assisting families in seeing the benefits of the transition, understanding the transition from the perspective of the family by maintaining the family-centered care perspective, elaborating on, and substantiating our role as occupational therapists at each level of the transition, as well as maintaining open lines of communication with families to form strong, satisfying and rewarding therapeutic relationships for the therapist, family, and ultimately for the child.

Conclusion

The transition of children with disabilities from EI to ECSE can be a stressful time for many families. The purpose of this inquiry has been to investigate parent perceptions of occupational therapy services in early childhood special education programs following transition from early intervention programs, and how these perceptions have changed over time. The case reports presented in Chapter IV included the perceptions of seven families regarding occupational therapy in the transition. Common themes across cases were presented in Chapter V to answer the study questions. As occupational therapists, it is important that we maintain the family-centered care approach throughout a families' EI experience as well as into the transition and beyond to help the family orient toward the future. As Kathy summarized:

"As parents and you have a child with a disability, there is no guidebook, there is no one there to help you along, so you are counting on a lot of professionals to turn you in the right direction."

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Appendix A

Self-As-Instrument Statement

As I embark in this research, I have identified several factors that could potentially influence my perspectives on this inquiry. These factors include my role as a parent of a child with developmental disabilities, my position as occupational therapist on the child intake team for the local school system and my position of treating therapist for prior transitioned preschoolers, as well as my role as advocate for those with developmental disabilities.

My first and most important role is that of a parent. My son's disabilities have brought to me first-hand the emotions and challenges of rearing a child with such disabilities and the often difficult task of acquiring federally mandated services in urban Louisiana and rural North Carolina in the late 1980's. It was this frustration that brought me to the profession of occupational therapy.

I have recently resumed my position as occupational therapist on the intake team for our local school system following a year of sabbatical leave. This role allows me to evaluate and make recommendations pertaining to children having developmental delays who are in the process of transitioning from early intervention to early childhood special education services. This is the most enjoyable aspect of my job and it was through this initial contact with parents of children having developmental delays that I tried to ease their anxieties regarding this major transition for them and their children. I also have the opportunity to provide occupational therapy intervention services for a small percentage of these children as a school-based therapist.

I am also an advocate. I advocate for services for persons with developmental disabilities and their families. I have served on the board of the Association for Retarded Citizens in a small town in North Carolina. It is through this role that I learned the difference between good, productive advocacy and negative, unproductive advocacy. Although I am no longer associated with this organization, I strive to be an effective, productive advocate for persons with developmental disabilities.

These experiences potentially bias my judgment as a researcher in ways that are not necessarily intended. I remained particularly attuned to these biases and strived to avoid influencing the responses of the participants by checking my responses to questions, participant responses, and mannerisms of participants throughout the interviewing and data analysis process.

Appendix B

Interview Guide and Questions

Criteria for Study

“I would like to first verify that you still meet the study criteria.” “Did your child receive services through an Early Intervention program in Virginia?” “What services did he/she receive?” “Does he/she receive services in an early childhood special education (preschool) program now?” “When did he/she transition to the ECSE program?” “What services does he/she receive as part of ECSE?”

Probes:

- ☐ Occupational Therapy, Physical Therapy, Speech Therapy, Vision Therapy
- ☐ Qualifying disability for services
- ☐ Current age of child, age transitioned to ECSE

Role and Benefit of Occupational Therapy

"I'd like to hear about your impression of ____________'s occupational therapy program at school and whether you feel that it has benefited him/her."

“What was your impression of OT in the Early Intervention program?”

Probes:

- ☐ Importance of OT
- ☐ Role of OT
- ☐ Differences between programs
- ☐ Parental satisfaction with ECSE and EI

Service Delivery

"And how often does _________ receive OT services now?" "How does that compare with his/her EI program?" “Please describe those services for me.”

Probes:

- ☐ Frequency
- ☐ Location of services
- ☐ Scheduling/when
- ☐ Difference b/w programs
- ☐ Family-centered/child-centered

Communication

"Can you tell me about the relationship that you have with your son's/daughter's OT? Do you communicate on any kind of regular basis?"

"How did you communicate with the OT in the early intervention program?" "How is it different?"

Probes:

- ☐ Type/extent
- ☐ Effectiveness/satisfaction with communication

Parental/Family Involvement

"What kinds of opportunities have you had to be involved in __________'s OT program? Have you taken the opportunity to get involved?"

"Describe your involvement with occupational therapy in the early intervention program, how was that different?"

Probes:

- ☐ Involved in IEP meeting, goal/objective development
- ☐ Participate/observe sessions
- ☐ Preferred level of involvement
- ☐ Activity packets, ideas for home

Transition

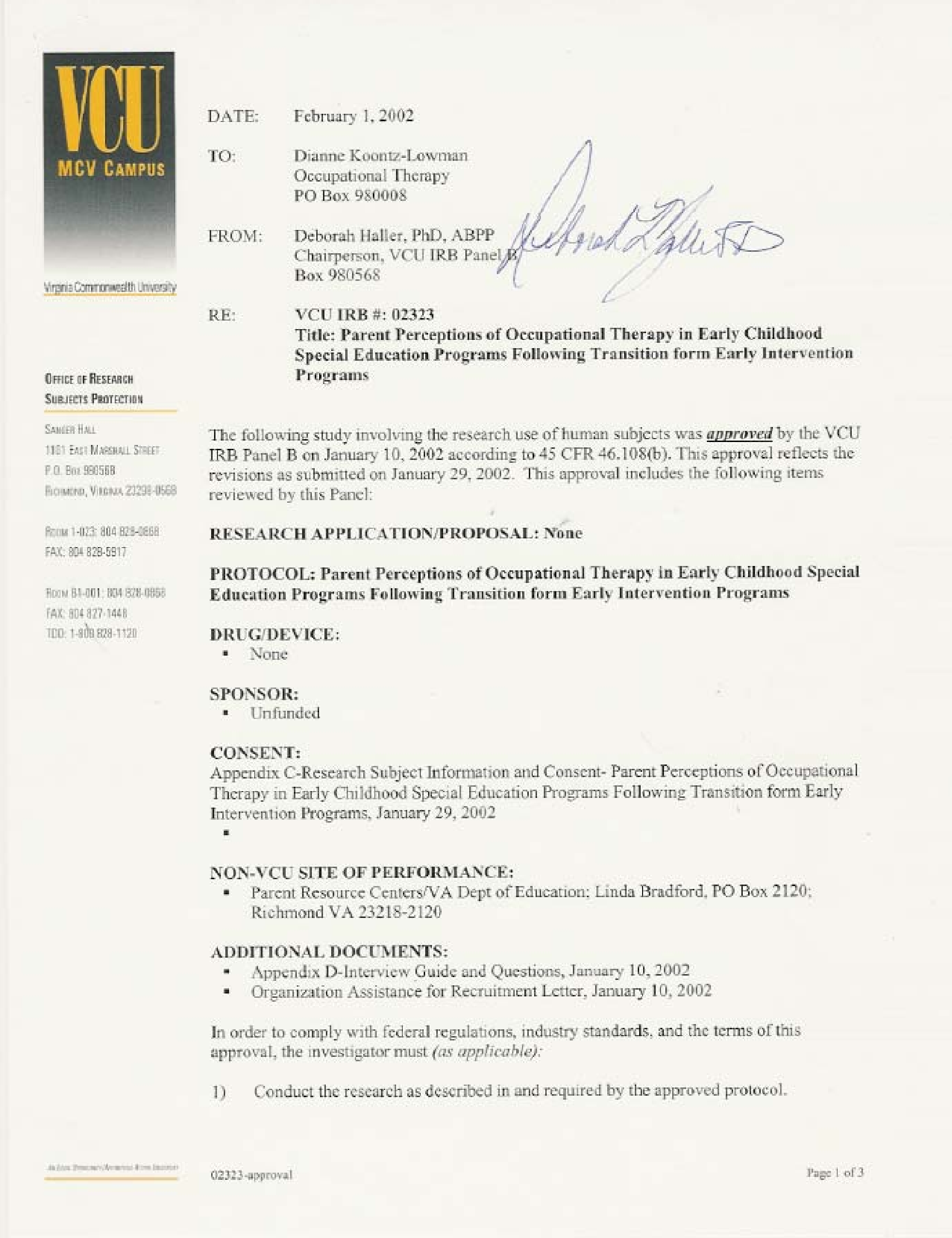
"Tell me about the transition process from EI services to preschool. Did you find the OTs helpful to you and to your child in making the change from one program to another?"

Probes:

- ☐ Difference in service delivery explained/questions answered
- ☐ Parent concerns with difference in service delivery
- ☐ Evaluations, record review, progress updated prior to transition
- ☐ Emotionality

Appendix C

Institutional Review Board Letter of Approval



VCU
MCV Campus
Virginia Commonwealth University

Office of Research
Subjects Protection

Sanger Hall
1101 East Marshall Street
P.O. Box 980568
Richmond, Virginia 23298-0568

Room 1-023: 804 828-0868
FAX: 804 828-5917

Room B1-001: 804 828-0868
FAX: 804 827-1448
TDD: 1-800 828-1120

DATE: February 1, 2002

TO: Dianne Koontz-Lowman
Occupational Therapy
PO Box 980008

FROM: Deborah Haller, PhD, ABPP
Chairperson, VCU IRB Panel B
Box 980568

RE: **VCU IRB #: 02323**
Title: Parent Perceptions of Occupational Therapy in Early Childhood Special Education Programs Following Transition form Early Intervention Programs

The following study involving the research use of human subjects was ***approved*** by the VCU IRB Panel B on January 10, 2002 according to 45 CFR 46.108(b). This approval reflects the revisions as submitted on January 29, 2002. This approval includes the following items reviewed by this Panel:

RESEARCH APPLICATION/PROPOSAL: None

PROTOCOL: Parent Perceptions of Occupational Therapy in Early Childhood Special Education Programs Following Transition form Early Intervention Programs

DRUG/DEVICE:
- None

SPONSOR:
- Unfunded

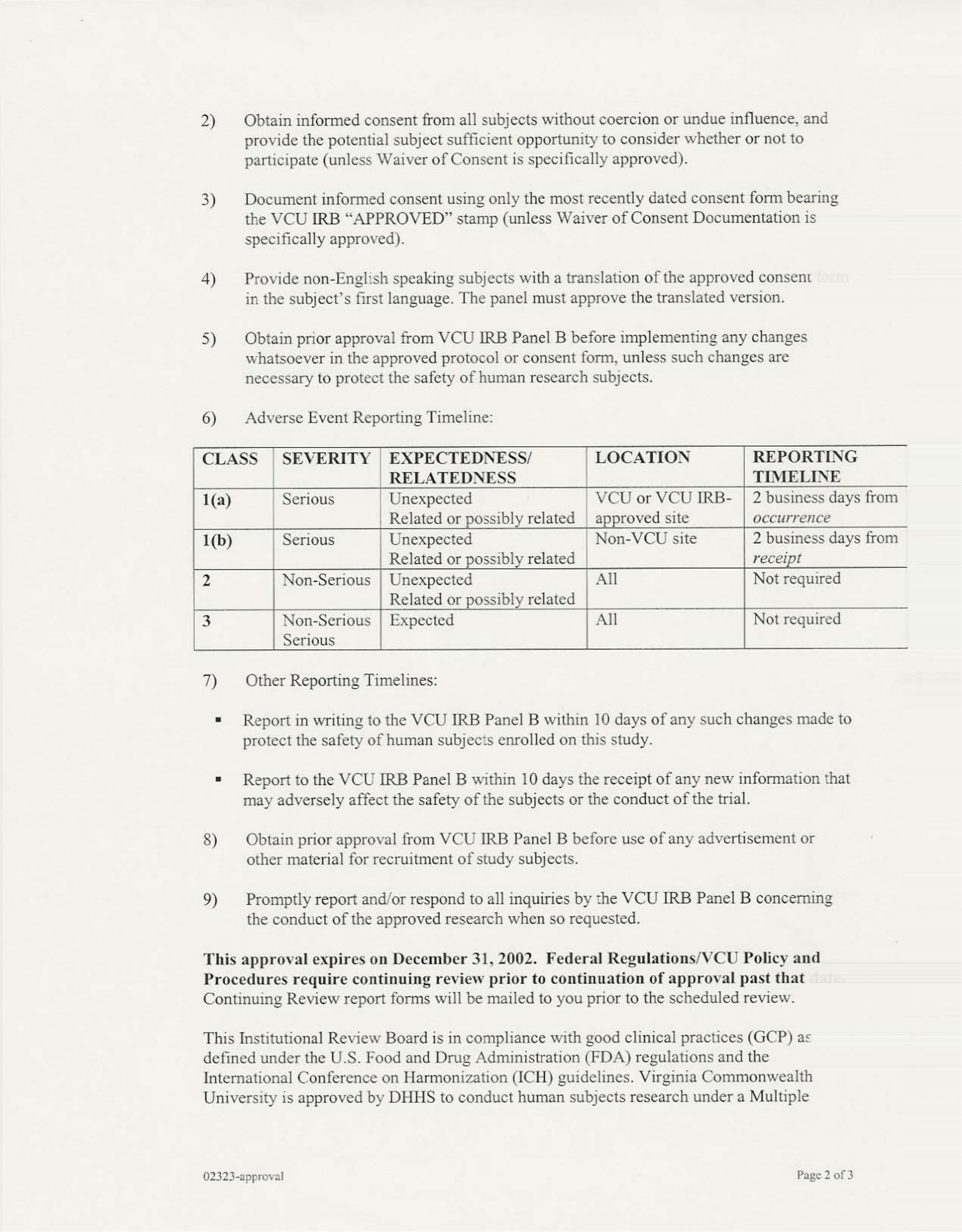
CONSENT:
Appendix C-Research Subject Information and Consent- Parent Perceptions of Occupational Therapy in Early Childhood Special Education Programs Following Transition form Early Intervention Programs, January 29, 2002
-

NON-VCU SITE OF PERFORMANCE:
- Parent Resource Centers/VA Dept of Education: Linda Bradford, PO Box 2120; Richmond VA 23218-2120

ADDITIONAL DOCUMENTS:
- Appendix D-Interview Guide and Questions, January 10, 2002
- Organization Assistance for Recruitment Letter, January 10, 2002

In order to comply with federal regulations, industry standards, and the terms of this approval, the investigator must *(as applicable):*

1) Conduct the research as described in and required by the approved protocol.



2) Obtain informed consent from all subjects without coercion or undue influence, and provide the potential subject sufficient opportunity to consider whether or not to participate (unless Waiver of Consent is specifically approved).

3) Document informed consent using only the most recently dated consent form bearing the VCU IRB "APPROVED" stamp (unless Waiver of Consent Documentation is specifically approved).

4) Provide non-English speaking subjects with a translation of the approved consent form in the subject's first language. The panel must approve the translated version.

5) Obtain prior approval from VCU IRB Panel B before implementing any changes whatsoever in the approved protocol or consent form, unless such changes are necessary to protect the safety of human research subjects.

6) Adverse Event Reporting Timeline:

CLASS	SEVERITY	EXPECTEDNESS/ RELATEDNESS	LOCATION	REPORTING TIMELINE
1(a)	Serious	Unexpected Related or possibly related	VCU or VCU IRB-approved site	2 business days from *occurrence*
1(b)	Serious	Unexpected Related or possibly related	Non-VCU site	2 business days from *receipt*
2	Non-Serious	Unexpected Related or possibly related	All	Not required
3	Non-Serious Serious	Expected	All	Not required

7) Other Reporting Timelines:

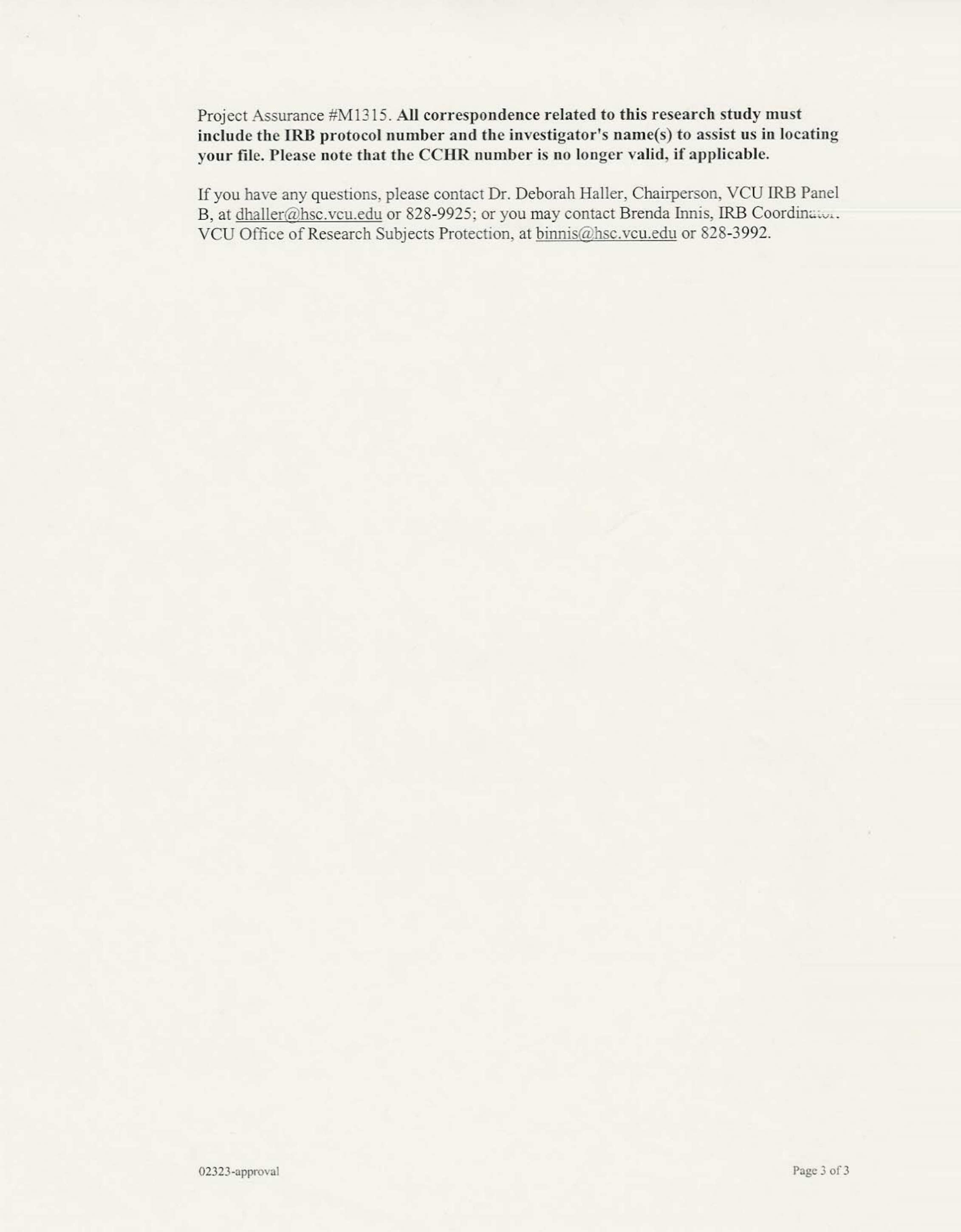
- Report in writing to the VCU IRB Panel B within 10 days of any such changes made to protect the safety of human subjects enrolled on this study.
- Report to the VCU IRB Panel B within 10 days the receipt of any new information that may adversely affect the safety of the subjects or the conduct of the trial.

8) Obtain prior approval from VCU IRB Panel B before use of any advertisement or other material for recruitment of study subjects.

9) Promptly report and/or respond to all inquiries by the VCU IRB Panel B concerning the conduct of the approved research when so requested.

This approval expires on December 31, 2002. Federal Regulations/VCU Policy and Procedures require continuing review prior to continuation of approval past that date. Continuing Review report forms will be mailed to you prior to the scheduled review.

This Institutional Review Board is in compliance with good clinical practices (GCP) as defined under the U.S. Food and Drug Administration (FDA) regulations and the International Conference on Harmonization (ICH) guidelines. Virginia Commonwealth University is approved by DHHS to conduct human subjects research under a Multiple

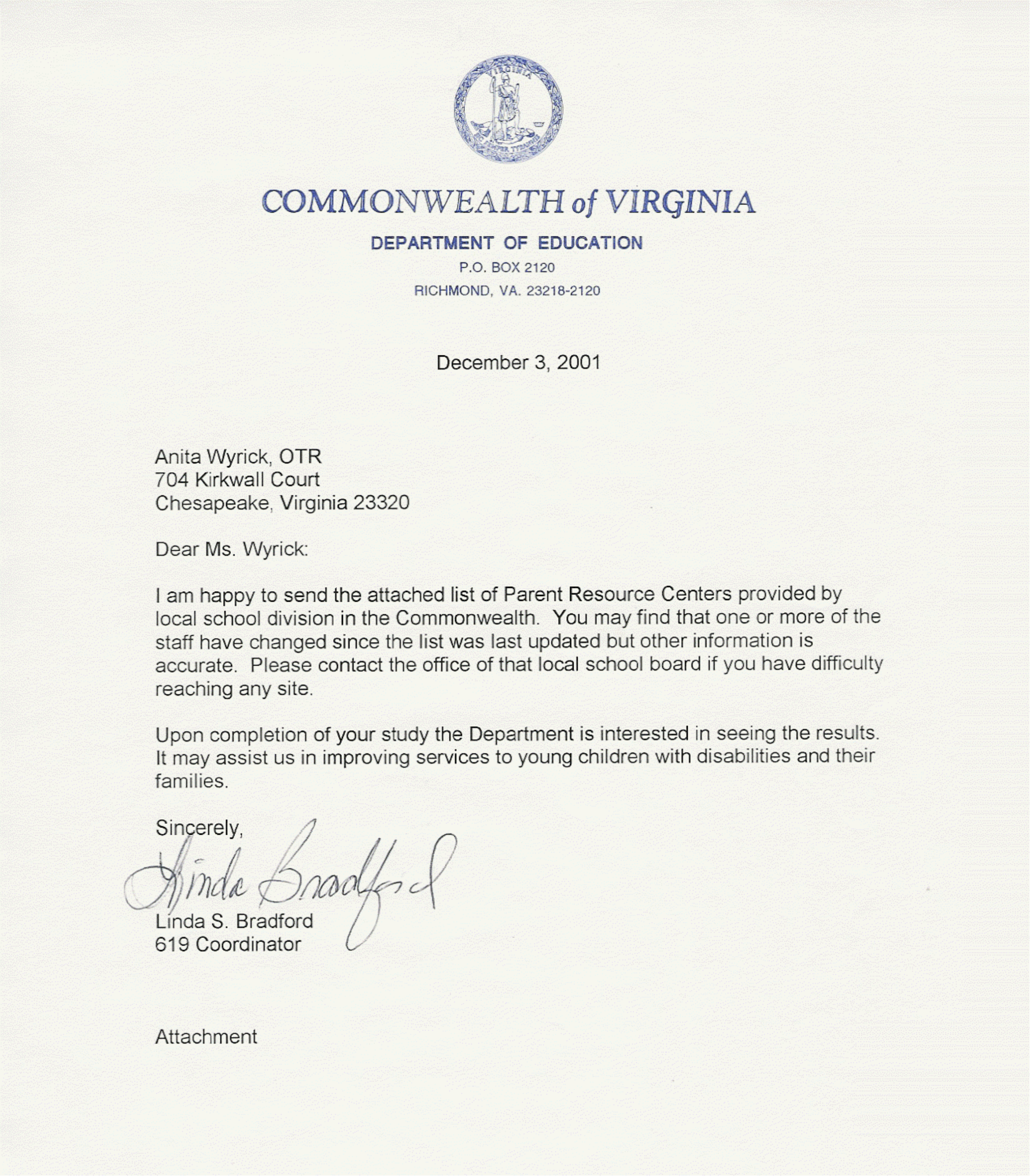


Project Assurance #M1315. **All correspondence related to this research study must include the IRB protocol number and the investigator's name(s) to assist us in locating your file. Please note that the CCHR number is no longer valid, if applicable.**

If you have any questions, please contact Dr. Deborah Haller, Chairperson, VCU IRB Panel B, at dhaller@hsc.vcu.edu or 828-9925; or you may contact Brenda Innis, IRB Coordinator, VCU Office of Research Subjects Protection, at binnis@hsc.vcu.edu or 828-3992.

Appendix D

Virginia Department of Education, Letter of Support



COMMONWEALTH of VIRGINIA
DEPARTMENT OF EDUCATION
P.O. BOX 2120
RICHMOND, VA. 23218-2120

December 3, 2001

Anita Wyrick, OTR
704 Kirkwall Court
Chesapeake, Virginia 23320

Dear Ms. Wyrick:

I am happy to send the attached list of Parent Resource Centers provided by local school division in the Commonwealth. You may find that one or more of the staff have changed since the list was last updated but other information is accurate. Please contact the office of that local school board if you have difficulty reaching any site.

Upon completion of your study the Department is interested in seeing the results. It may assist us in improving services to young children with disabilities and their families.

Sincerely,

Linda Bradford

Linda S. Bradford
619 Coordinator

Attachment

VIRGINIA DEPARTMENT OF EDUCATION
OFFICE OF SPECIAL EDUCATION AND STUDENT SERVICES

PARENT/EDUCATOR RESOURCE CENTER ROSTER

(REVISED August 23, 2001)

Virginia Department of Education
Office of Special Education and Student Services
Parent/Educator Resource Center Roster
2000-2001

SCHOOL DIVISION	NAME	ADDRESS	PHONE
ALEXANDRIA CITY PRC	ANNE LIPNICK, COORDINATOR	JEFFERSON-HOUSTON ELEM 1501 CAMERON ST ALEXANDRIA VA 22314	(703) 706-4400 (OFFICE) (703) 461-4188 (VOICE MAIL) (703) 836-7923 (FAX) alipnick@acps.k12.va.us
ALLEGHANY COUNTY COVINGTON PRC	ANITA EGGLESTON, COORDINATOR	P O BOX 533 CLIFTON FORGE VA 24422	(540) 863-1621
ARLINGTON PUBLIC SCHOOLS PRC	COLLEEN SHEPPARD, PARENT KATHLEEN DONOVAN, EDUCATOR	2801 CLARENDON BLVD SUITE 304 ARLINGTON, VA 22201	(703) 228-7239 (OFFICE) (703) 525-4847 (FAX) prc@arlington.k12.va.us www.arlington.k12.va.us/departments/specialed/prc
BRUNSWICK COUNTY PRC	MELISSA POWERS BEVERLY WHITE ALICIA STITH	236 SCHOOL DAYS DRIVE LAWRENCEVILLE VA 23868	(434) 848-2157 (OFFICE) (434) 848-6205 (FAX)
CAROLINE COUNTY PRC	SUSAN GAYLE, PARENT MARCIE LEWIS, EDUCATOR	CAROLINE MIDDLE SCHOOL 13325 DEVILS THREE JUMP ROAD MILFORD VA 22514 MAILING ADDRESS: 16221 RICHMOND TURNPIKE BOWLING GREEN VA 22427	(804) 633-7083 (OFFICE) (804) 633-5563 (FAX) sgayle@caroline.k12.va.us
CHESAPEAKE CITY PRC	LAEUNICE BROWN, INFO SPCLTS CATHY BURGH, INFO SPCLTS	PARENT RESOURCE CENTER 369 S BATTLEFIELD BLVD CHESAPEAKE VA 23322	(757) 482-5923 (OFFICE) (757) 546-0990 brownlag@cps.k12.va.us burghcpa@cps.k12.va.us
CHESTERFIELD COUNTY PRC	DEBI MILES, PARENT CHARLENE LEE, EDUCATOR	PARENT RESOURCE CENTER 4003 COGBILL ROAD RICHMOND VA 23234	(804) 743-3703 (OFFICE) (804) 743-7169 (FAX) debimiles@chesterfield.k12.va.us cmlee@chesterfield.k12.va.us

SCHOOL DIVISION	NAME	ADDRESS	PHONE
COLONIAL HEIGHTS PRC	JUDY DEBOER, PARENT (VACANT), EDUCATOR	COLONIAL HEIGHTS MID SCH 500 CONDUIT ROAD COLONIAL HEIGHTS VA 23834	(804) 524-3452 (OFFICE) (804) 526-9288 (FAX) judy_deboer@colonialhts.net
CULPEPER COUNTY PRC	DEBRA SWITZER, PARENT SHARON LAM, EDUCATOR	PEARL SAMPLE ELEMENTARY 18480 SIMMS DRIVE CULPEPER VA 22701	(504) 829-2108 ptrc99@hotmail.com
FAIRFAX COUNTY INCLUDES:	MARSHA GOLDBERG, EDUCATOR	DUNN LORING ADM EDUCATION 2334 GALLOWS ROAD DUNN LORING VA 22027	(703) 204-3941 (OFFICE) (703) 641-9213 (FAX) mgoldberg@area3off.fcps.k12.va.us
AREA 1:	KATHY ANDRUS, PARENT LIASON	HAYFIELD ELEMENTARY 7633 TELEGRAPH RD ALEXANDRIA VA 22315	(703) 924-4512 kda100@hotmail.com
AREA 2:	KIM MCCOMAS, PARENT LIASON	POPLAR TREE ELEMENTARY 13440 MELVILLE LANE CHANTILLY VA 20151	(703) 802-2069 cleftwich@fc.fcps.k12.va.us
AREA 3:	CLAIRE LEFTWICH, PARENT LIASON	DUNN LORING ADM	(703) 204-3941 (OFFICE) (703) 641-9213 (FAX) kmccomas@fc.fcps.k12.va.us
FRANKLIN COUNTY PRC	JANICE DARNELL, PARENT MARSHALL FLORA, EDUCATOR	25 SCHOOL SERVICE RD EXT ROCKY MOUNT VA 24515 6614	(540) 483-0280 (OFFICE) (540) 483-4202 (FAX)
FREDERICK COUNTY PRC	SUSIE GEROMETTA, PARENT DEBBIE MOSS, EDUCATOR	403 B SOUTH LOUDOUN ST WINCHESTER VA 22601	(540) 535-9006 (OFFICE) mossd@frederick.k12.va.us
GILES COUNTY PRC	KAREN MCCRAW, PARENT BROOKS FULLEN, EDUCATOR	MACY MCCLAUGHERTY SCHOOL 1001 HENSON AVENUE PEARISBURG VA 24134	(540) 921-1912 OR 626-7287 (OFFICE) (540) 921-2085 (FAX) kmccraw@mms.giles.k12.va.us
GOOCHLAND COUNTY PRC	PAM NULL, PARENT JAYNE HANCOCK, EDUCATOR	GOOCHLAND MIDDLE SCHOOL 2748 DOGTOWN ROAD GOOCHLAND VA 23603	(804) 556-4867 (OFFICE) (804) 556-5320 (GMS)
HAMPTON CITY PRC	JACQUELINE HENDERSON, PARENT, SUSIE HENDERSON & CINDI BROSKIE, EDUCATORS	1819 NICKERSON BLVD HAMPTON VA 23663	(757) 850-5161 (OFFICE)

SCHOOL DIVISION	NAME	ADDRESS	PHONE
HANOVER COUNTY PRC	BETSY PHILLIPS, COORDINATOR SUSIE CHENAULT, CONSULTANT	JOHN M GANDY ELEMENTARY 201 ARCHIE CANNON DRIVE ASHLAND VA 23005	(804) 365-4596 (OFFICE) (804) 365-4659 (FAX) hanoverprc@hanover.k12.va.us
HENRICO COUNTY PRC	JANE CARLUCCI, PARENT, SHERRIE CHASE, PARENT, SUSAN STANLEY, EDUCATOR	MATH/SCIENCE CENTER BUILDING F 2401 HARTMAN STREET RICHMOND VA 23223	(804) 343-6523 (OFFICE) (804) 343-6515 (FAX)
HENRY COUNTY PRC	PATTY O'BRIEN	EDUCATION STATION LIBERTY FAIR MALL 240 WEST COMMONWEALTH BLVD UNIT 72 MARTINSVILLE VA 24112	(540) 632-7248
HOPEWELL CITY PRC	BRENDA ATKINS, PARENT ANNA NOLAND, EDUCATOR	HARRY E JAMES ELEMENTARY LIBRARY CONFERENCE ROOM 1807 ARLINGTON RD HOPEWELL VA 23860	(804) 541-6443 (OFFICE) (804) 541-6409 (FAX)
KING GEORGE COUNTY PRC	LAWANDA WRIGHT, PARENT LISA COLE, EDUCATOR	9100 ST ANTHONYS ROAD MAILING: P O BOX 1239 KING GEORGE VA 22485	(540) 775-0589 (OFFICE) (540) 775-2165 (FAX)
LEXINGTON/BUENA VISTA/ROCKBRIDGE REGIONAL PRC	DEBORAH WOODY MASCHAL, LEXINGTON EDUCATOR LINDA BAUMANN, ROCKBRIDGE PARENT	123 SOUTH RANDOLPH STREET LEXINGTON VA 24450	(540) 464-8560 (OFFICE)
LOUDOUN COUNTY PRC	LINDA ROBEY, PARENT GAIL GROY, EDUCATOR	BALLS BLUFF ELEMENTARY SCH 821 BATTLEFIELD PARKWAY N E LEESBURG VA 20176	(703) 771-6765 (OFFICE) (703) 779-8804 (FAX)
LYNCHBURG CITY PRC	BARBARA PARKS, COORDINATOR	P O BOX 1599 1101 COURT STREET LYNCHBURG VA 24505	(434) 522-3737 (OFFICE)

SCHOOL DIVISION	NAME	ADDRESS	PHONE
POQUOSON CITY PRC	KIM MESSICK, PARENT GAIL ELMAKIS, EDUCATOR	POQUOSON ELEMENTARY SCH 1033 POQUOSON AVENUE ROOM 7 POQUOSON VA 23662	(757) 868-7564 (OFFICE) (757) 868-8058 (FAX)
POWHATAN COUNTY PRC	JOANNE EASTWOOD, PARENT LISA OXLEY, EDUCATOR	POWHATAN ELEMENTARY SCH 4111 OLD BUCKINGHAM ROAD POWHATAN VA 23139	(804) 598-3034 (OFFICE) (804) 598-1484 (FAX) loxley@powhatan .k12.va.us
PRINCE GEORGE COUNTY PRC	GLENDA BISHOP, PARENT SUSAN NOLL, EDUCATOR	JEJ MOORE MIDDLE SCHOOL 11455 PRINCE GEORGE DRIVE ROOM B 23 DISPUTANTA VA 23842	(804) 733-2698 (OFFICE) (804) 732-1172 (FAX)
PRINCE WILLIAM COUNTY PRC	BETTY ANN MAHER, PARENT JOHN BASS, EDUCATOR	PRINCE WILLIAM CO PRC PENNINGTON SCHOOL 9305 STONEWALL ROAD MANASSAS VA 20110	(703) 393-6719 (OFFICE) (703) 369-4206 (FAX) maherba@pwcs.edu bassj@pwcs.edu www.pwcs.edu
PULASKI COUNTY PRC	JACQUELINE FAGAN MYAL, PARENT (VACANT), EDUCATOR	LOCATION: PRESCHOOL CENTER 205 6TH STREET DUBLIN VA 24084 MAILING: 44 3RD ST NW PULASKI VA 24301	(540) 674-4574 (OFFICE) (540) 980-8717 (FAX)
RADFORD CITY PRC	KELLY HAGY, PARENT CHERYL SHULL, EDUCATOR, KENDRA SABO, EDUCATOR	BELLE HETH SCHOOL 810 SECOND AVENUE RADFORD VA 24141	(540) 731-3679 (OFFICE)
RICHMOND CITY PRC	MALINDA CONRAD, PARENT	AMELIA STREET SCHOOL 1821 AMELIA STREET RICHMOND VA 23220-6696	(804) 780-6220 (OFFICE) (804) 780-8775 (FAX) RICHPRC2000@aol.com
ROANOKE CITY PRC	SHIRL LIGHT, PARENT JULIA ARTRIP, PARENT (VACANT), EDUCATOR	40 DOUGLAS AVENUE ROANOKE, VA 24012	(540) 853-2089 (OFFICE) (540) 853-2469 (FAX)

SCHOOL DIVISION	NAME	ADDRESS	PHONE
ROANOKE COUNTY PRC	LYNN SHERMAN, PARENT ELIZABETH VINCEL, EDUCATOR	4902 HIDDEN VALLEY SCHOOL RD ROANOKE VA 24018	(540) 772-2161 (OFFICE) (540) 772-7519 (FAX)
RUSSELL COUNTY PRC	JUDY LEBLANC, PARENT RITA BANNER, EDUCATOR	LOCATION: RUSSELL CO LIBRARY E MAIN STREET LEBANON VA 24266 MAILING: SCHOOL BOARD DRIVE LEBANON VA 24266	(540) 889-6500 (OFFICE)
SALEM CITY PRC	(VACANT), PARENT DR. LEWIS D ROMANO, EDUCATOR	510 SOUTH COLLEGE AVENUE SALEM VA 24153	(540) 389-0130 (OFFICE)
SMYTH COUNTY PRC (INACTIVE)	(VACANT), PARENT (VACANT), EDUCATOR	221 LOOK AVENUE MARION VA 24354	(540) 783-4183 (OFFICE)
SPOTSYLVANIA COUNTY PRC	SANDY SPRAGUE, PARENT PEGGY DOUGHERTY, EDUCATOR	7409 BROCK ROAD SPOTSYLVANIA VA 22553	(540) 582-3616 (OFFICE) (540) 582-3791 (FAX) pdougher@spotsylvania.k12.va.us ssprague@spotsylvania.k12.va.us
STAFFORD COUNTY PRC	BECCA LEGGITT, PARENT REBECCA CARSWELL, EDUCATOR	PARENT RESOURCE CENTER HEADSTART BUILDING 37 STAFFORD AVENUE STAFFORD VA 22554	(540) 658-6448 (OFFICE) (540) 658-6439 (FAX) staffordprc@staffnet.com
SUFFOLK CITY PRC	DEBRA BAGLEY, PARENT DORA PEARSON, EDUCATOR	121 FOREST GLEN DRIVE SUFFOLK VA 23434	(757) 925-5579 (OFFICE) (757) 925-5612 (FAX)
VIRGINIA BEACH CITY PRC	GLORIA OATES, PARENT RUTH PAGE, EDUCATOR	1413 LASKIN ROAD VIRGINIA BEACH VA 23451	(757) 437-6539 (EXT. 156 AND 157) (757) 437-6533 (OFFICE) (757) 437-6540 (FAX)
WILLIAMSBURG/JAMES CITY PRC	SUZANNE STUART, PARENT ELLEN HARPER, EDUCATOR	3925 MIDLANDS ROAD WILLIAMSBURG VA 23188	(757) 220-5325 (OFFICE) (757) 253-0129 stuarts@wjcc.k12.va.us

Appendix E

Organization Solicitation Letter

Anita M. Wyrick
704 Kirkwall Ct.
Chesapeake, VA 23320

(Date)

Dear (Parent Resource Center Staff Member):

I am an occupational therapist and graduate student at Virginia Commonwealth University (VCU). I have been given your name by Linda Bradford at the Virginia Department of Education as potentially providing me assistance in locating families for participation in my thesis research entitled *Parent Perceptions of Occupational Therapy Services in Early Childhood Special Education Programs following Transition from Early Intervention Programs*.

I am seeking the parents of children with disabilities or developmental delay receiving occupational therapy (OT) services in an Early Childhood Special Education Programs and who have also formally received OT services in an Early Intervention Program in Virginia. Parents should be English speaking. Because of your contact with families in your district, it is my hope that you will be willing to assist me in locating families that meet my study criteria. This can be accomplished in one of two ways: First, I can address one of your organizational meetings (likely in January or February, 2002) and describe to the attending families the study and solicit their participation. I will provide a written description of the study at that time. Secondly, I can provide you with a written description of the study along with pre-addressed, posted envelopes for you to pass along to families that may meet the study criteria as you encounter them in your center. Alternatively, you can contact by telephone families who are known to you who may be interested in the study, asking them to call me, or asking permission to pass along their name and phone number so that I may contact them. You may find a combination of these techniques will work best.

This study has been approved by the Institutional Review Board at VCU, which oversees the conduct of human research, and is directed by Dr. Dianne Koontz Lowman, Assistant Professor, Dept. of Occupational Therapy at VCU. All information will be kept confidential and no identifying information will be revealed.

I would very much like your assistance in locating families for this study. I am enclosing a copy of the study description to give you a better idea of what will be involved. Also, I would like the opportunity to discuss your involvement with you should you have any questions. Please call me at your earliest convenience (collect), (757) 547-1767 so that we may discuss the details. In any event, I will be contacting you in the next few weeks. I look forward to hearing from you. You can also contact Dr. Dianne Koontz Lowman, study director, at (804) 828-2219 at the VCU Department of Occupational Therapy should you have any questions that you feel require her attention. Thank you for your consideration to this matter.

Sincerely,

Anita M. Wyrick, OTR

Appendix F

Research Description Letter

January, 2002

Study on Parent Perceptions of Occupational Therapy

Study Description and Invitation for Your Participation

Dear Parent:

As you know, Occupational Therapy encourages your involvement in your child's services. We would like to ask for your help in completing a study called *Parent Perceptions of Occupational Therapy Services in Early childhood Special Education Programs Following Transition from Early Intervention Programs.* We are looking for the following:

- ☐ Parents of children with disabilities or developmental delay who get occupational therapy (OT) services in an Early Childhood Special Education Program (sometimes called preschool) **AND** who have received OT in an Early Intervention Program in Virginia (sometimes called the infant program or home services)

- ☐ Parents must be English Speaking

If you checked the above boxes, we would like you to think about helping us in this study.

The purpose of this study is to find out what parents think and how they feel about occupational therapy services in their child's preschool program after leaving the early intervention program and how your thoughts and feelings may have changed. We would also like to find out what you think the role of OT is or should be during the move from the early intervention program. And get your opinion about OT services for your child and how you communicate and help with your child's occupational therapist.

Anita Wyrick, an occupational therapist and graduate student at Virginia Commonwealth University (VCU) will conduct the study. Dr. Dianne Koontz Lowman, assistant professor at VCU, will direct the study. VCU's Committee for the Conduct of Human Research has approved the study.

Your participation would include being asked questions in your home. The interview may last 60-90 minutes. The interview will be tape-recorded but the tape will be destroyed after the study. In the interview you will be asked questions about how you feel about occupational therapy, the early intervention program, and your child's preschool program. You will also be asked about your thoughts and feelings about how occupational therapy helped during the transition from the infant program to the preschool program. You may be asked to be interviewed later over the telephone or at your home. This follow-up interview may last 60 minutes.

It is your choice to participate in this study. You can withdraw at any time. All information you share will be confidential. Your name will be changed to protect your identity. You will be given more information about the study and answers to your questions. You will also be asked to sign a permission form before the study is started. Some of the questions asked in the interview may be upsetting, but this study has no risk to your physical health.

You may enjoy the chance to share your experiences and get new ideas as you talk about your experiences with your child and with various programs. Your help in this study may provide important information that may help other families.

If you think you would like to take part in this study, please call Anita Wyrick, occupational therapist, (collect) at 757-547-1767. Or write your name, address and phone number below and mail it to the address given. If you would like to think it over or talk about it with someone you trust, you can call or mail the information later. If you have any more questions you can call Anita Wyrick at the number above. We hope you will give some thought to helping us with this study. We look forward to speaking with you if you choose to help out.

Sincerely,

Anita Wyrick, OTR Dianne Koontz Lowman, Ed.D

PARENT STUDY REGISTRATION

Yes, I am interested in helping with the study:

Name____ Phone(___)_____________

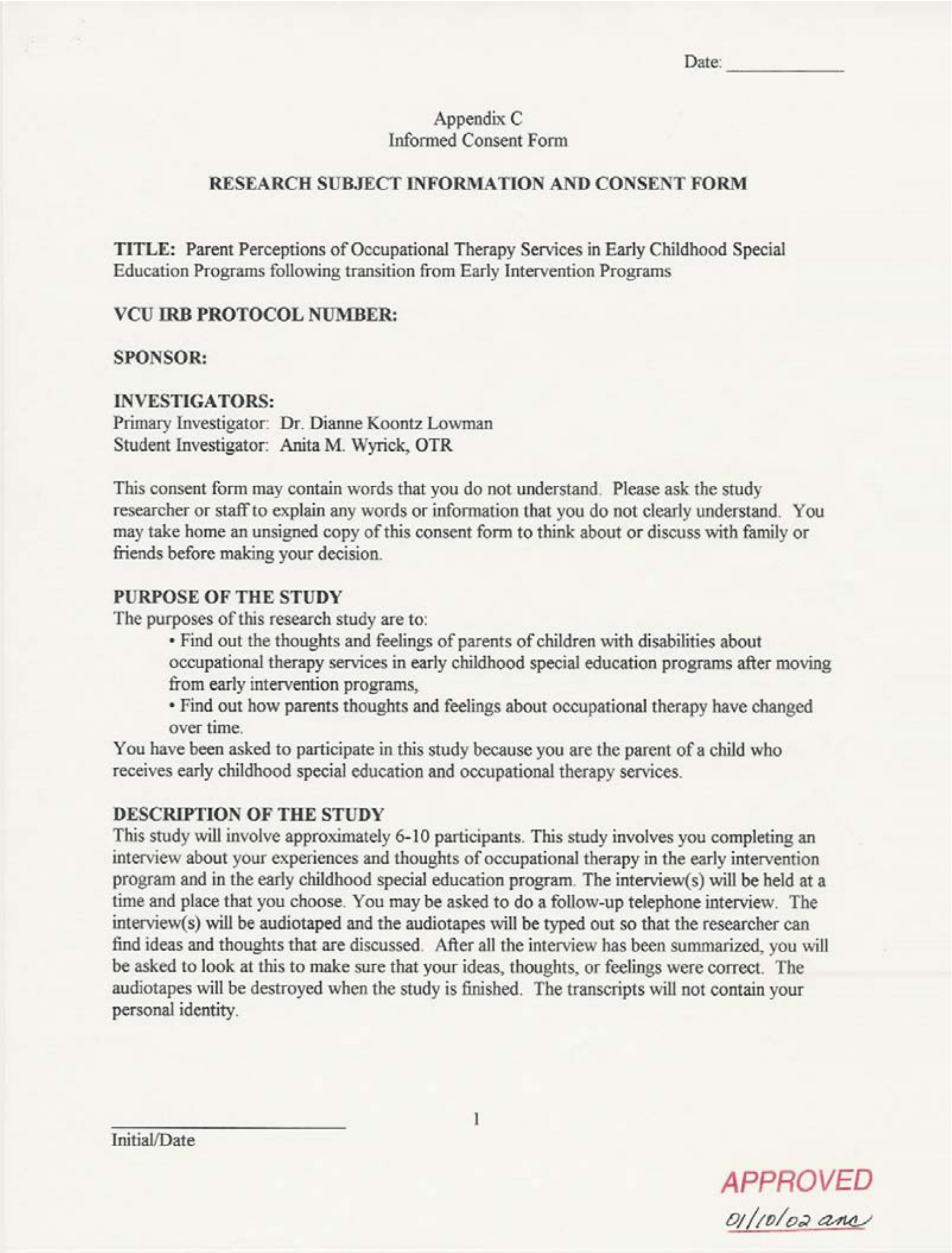
Address____

Please mail this form to:

Anita Wyrick, OTR
704 Kirkwall Ct.
Chesapeake, VA 23320

Appendix G

Informed Consent Form



Date: ____________

Appendix C
Informed Consent Form

RESEARCH SUBJECT INFORMATION AND CONSENT FORM

TITLE: Parent Perceptions of Occupational Therapy Services in Early Childhood Special Education Programs following transition from Early Intervention Programs

VCU IRB PROTOCOL NUMBER:

SPONSOR:

INVESTIGATORS:
Primary Investigator: Dr. Dianne Koontz Lowman
Student Investigator: Anita M. Wyrick, OTR

This consent form may contain words that you do not understand. Please ask the study researcher or staff to explain any words or information that you do not clearly understand. You may take home an unsigned copy of this consent form to think about or discuss with family or friends before making your decision.

PURPOSE OF THE STUDY
The purposes of this research study are to:

- Find out the thoughts and feelings of parents of children with disabilities about occupational therapy services in early childhood special education programs after moving from early intervention programs,
- Find out how parents thoughts and feelings about occupational therapy have changed over time.

You have been asked to participate in this study because you are the parent of a child who receives early childhood special education and occupational therapy services.

DESCRIPTION OF THE STUDY
This study will involve approximately 6-10 participants. This study involves you completing an interview about your experiences and thoughts of occupational therapy in the early intervention program and in the early childhood special education program. The interview(s) will be held at a time and place that you choose. You may be asked to do a follow-up telephone interview. The interview(s) will be audiotaped and the audiotapes will be typed out so that the researcher can find ideas and thoughts that are discussed. After all the interview has been summarized, you will be asked to look at this to make sure that your ideas, thoughts, or feelings were correct. The audiotapes will be destroyed when the study is finished. The transcripts will not contain your personal identity.

1

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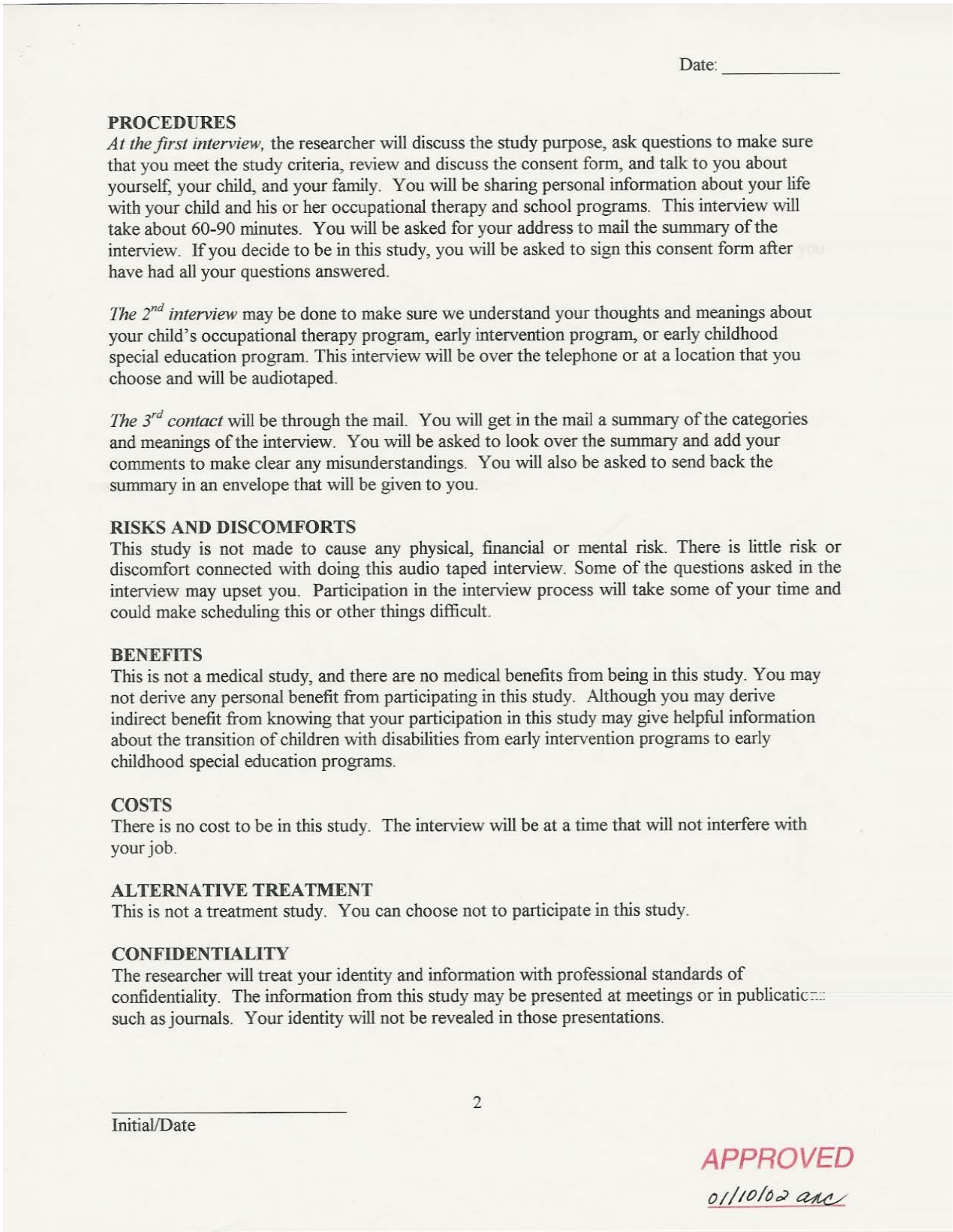
Initial/Date

APPROVED
01/10/02 anc



Date: ____________

PROCEDURES
At the first interview, the researcher will discuss the study purpose, ask questions to make sure that you meet the study criteria, review and discuss the consent form, and talk to you about yourself, your child, and your family. You will be sharing personal information about your life with your child and his or her occupational therapy and school programs. This interview will take about 60-90 minutes. You will be asked for your address to mail the summary of the interview. If you decide to be in this study, you will be asked to sign this consent form after you have had all your questions answered.

The 2nd interview may be done to make sure we understand your thoughts and meanings about your child's occupational therapy program, early intervention program, or early childhood special education program. This interview will be over the telephone or at a location that you choose and will be audiotaped.

The 3rd contact will be through the mail. You will get in the mail a summary of the categories and meanings of the interview. You will be asked to look over the summary and add your comments to make clear any misunderstandings. You will also be asked to send back the summary in an envelope that will be given to you.

RISKS AND DISCOMFORTS
This study is not made to cause any physical, financial or mental risk. There is little risk or discomfort connected with doing this audio taped interview. Some of the questions asked in the interview may upset you. Participation in the interview process will take some of your time and could make scheduling this or other things difficult.

BENEFITS
This is not a medical study, and there are no medical benefits from being in this study. You may not derive any personal benefit from participating in this study. Although you may derive indirect benefit from knowing that your participation in this study may give helpful information about the transition of children with disabilities from early intervention programs to early childhood special education programs.

COSTS
There is no cost to be in this study. The interview will be at a time that will not interfere with your job.

ALTERNATIVE TREATMENT
This is not a treatment study. You can choose not to participate in this study.

CONFIDENTIALITY
The researcher will treat your identity and information with professional standards of confidentiality. The information from this study may be presented at meetings or in publications such as journals. Your identity will not be revealed in those presentations.

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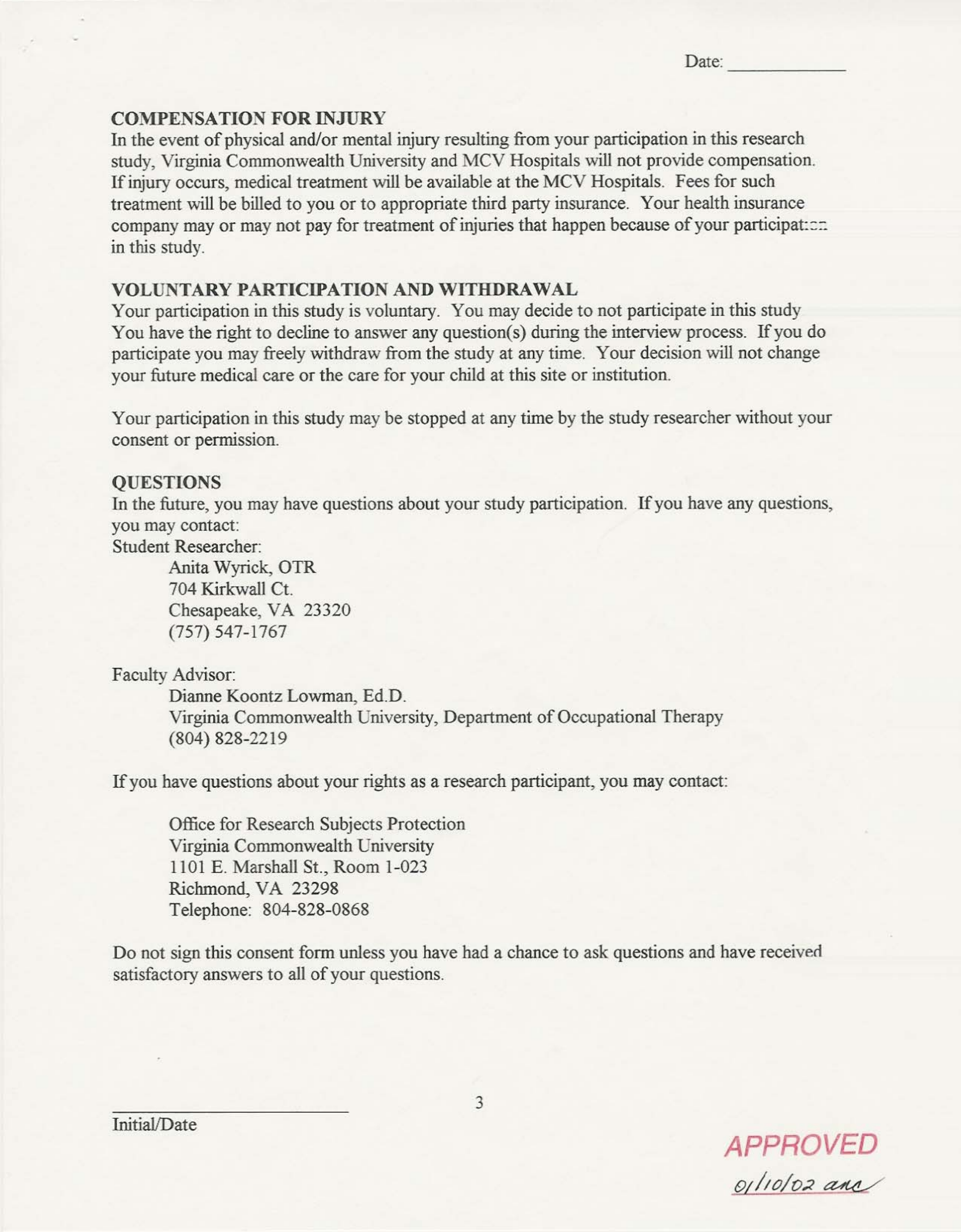
Initial/Date

APPROVED
01/10/02 anc



Date: ____________

COMPENSATION FOR INJURY
In the event of physical and/or mental injury resulting from your participation in this research study, Virginia Commonwealth University and MCV Hospitals will not provide compensation. If injury occurs, medical treatment will be available at the MCV Hospitals. Fees for such treatment will be billed to you or to appropriate third party insurance. Your health insurance company may or may not pay for treatment of injuries that happen because of your participation in this study.

VOLUNTARY PARTICIPATION AND WITHDRAWAL
Your participation in this study is voluntary. You may decide to not participate in this study You have the right to decline to answer any question(s) during the interview process. If you do participate you may freely withdraw from the study at any time. Your decision will not change your future medical care or the care for your child at this site or institution.

Your participation in this study may be stopped at any time by the study researcher without your consent or permission.

QUESTIONS
In the future, you may have questions about your study participation. If you have any questions, you may contact:
Student Researcher:
Anita Wyrick, OTR
704 Kirkwall Ct.
Chesapeake, VA 23320
(757) 547-1767

Faculty Advisor:
Dianne Koontz Lowman, Ed.D.
Virginia Commonwealth University, Department of Occupational Therapy
(804) 828-2219

If you have questions about your rights as a research participant, you may contact:

Office for Research Subjects Protection
Virginia Commonwealth University
1101 E. Marshall St., Room 1-023
Richmond, VA 23298
Telephone: 804-828-0868

Do not sign this consent form unless you have had a chance to ask questions and have received satisfactory answers to all of your questions.

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Initial/Date

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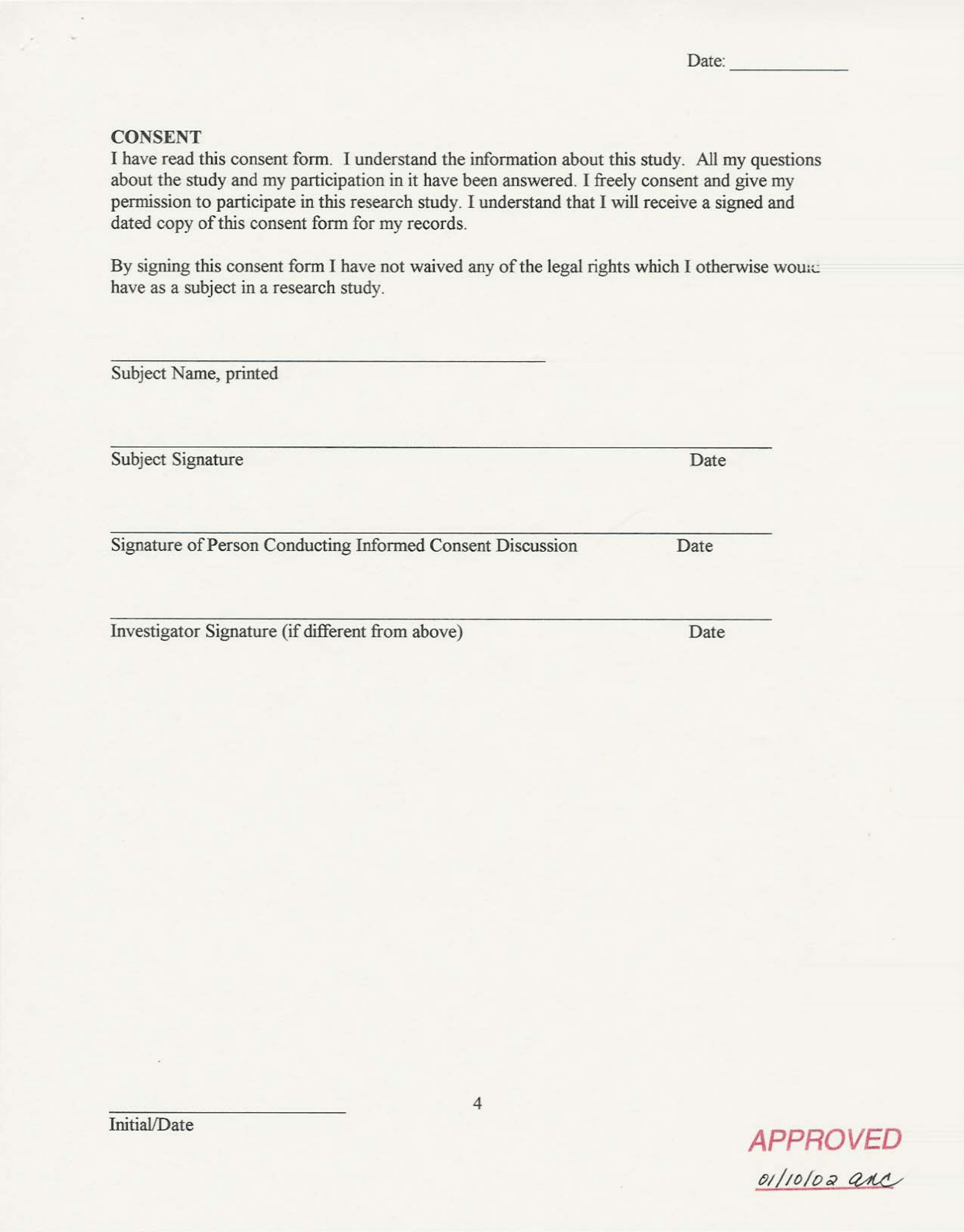

Date: ____________

CONSENT
I have read this consent form. I understand the information about this study. All my questions about the study and my participation in it have been answered. I freely consent and give my permission to participate in this research study. I understand that I will receive a signed and dated copy of this consent form for my records.

By signing this consent form I have not waived any of the legal rights which I otherwise would have as a subject in a research study.

____
Subject Name, printed

____
Subject Signature Date

____
Signature of Person Conducting Informed Consent Discussion Date

____
Investigator Signature (if different from above) Date

4

____
Initial/Date

APPROVED
01/10/02 anc

Appendix H

Written Expression of Gratitude

Anita M. Wyrick
704 Kirkwall Ct.
Chesapeake, VA 23320

(DATE)

Dear (participant name):

It was certainly a pleasure to meet with you on (day). I wanted to take a moment to offer you my sincere thanks for taking time away from your busy day to meet with me and describe your experiences and feelings regarding your child's preschool program and occupational therapy services. Your perceptions and experiences are very important to me. As such, I want to ensure you that I have made every attempt to reflect the thoughts and feelings that you expressed in our interview in a way that capture the meaning of your comments. I am enclosing a copy of the summary of our interview and my interpretations of such. You can make comments for clarification on the margin or on a separate sheet of paper and I will likely contact you by phone to make sure I understand your clarification. In any event, simply return the summary in the enclosed pre-posted envelope. Please do this at your earliest convenience.

Again, I sincerely appreciate your time and effort in helping me to accomplish this important research study. Please don't hesitate to call me, 757-547-1767, if you have any questions or concerns regarding this study, now or in the future.

Sincerely,

Anita M. Wyrick, OTR/L

Appendix I

Talking Points

Themes and Talking Points

1) Transition from EI services to ECSE services is viewed positively when parents are able to see benefits of the change for their child and when they are oriented toward the future.

- Transition is a process of letting go of the familiar and accepting the unfamiliar…ECSE was unfamiliar for parents of children with disabilities
- Lack of familiarity with the school system (ECSE) led to uncomfortable feelings and uncertainty of what to expect
- Parents who can "see" benefits for child (i.e., socialization, respite, language models, inclusion) were more positive about transition.
    - One mother said, "She needs to go, move on. For the socialization…just the variety…she's so social and so verbal she had people to talk to and…she was gonna get a fuller four hours. I was excited. I so much needed that break." (Courtney)
- Parents who were comfortable with EI and not "looking for more" had a harder time with transition (i.e., loss of professional support, involvement in therapy, medical problems/fragility). (Wanda, Valerie and Chuck).
    - One father said, "We weren't really wanting to do it [transition] anyway because we thought he was getting quite good care where he was at. We didn't think he was ready and we weren't ready for him to go to school." (Chuck and Valerie)

2) Parents view the EI and ECSE Systems as not sharing their same perspective on their child's transition.

- Early intervention and preschool (EI and ECSE) systems focused on system level issues such as paperwork referrals, records transfer, scheduling visits, meetings, etc.
- Families focused on child and family specific issues such as transportation, medical emergencies, feeding, and knowing who would work with their child.

- Details that were concerning to families were left unaddressed by the systems set up to serve them, leaving families to find solutions and answers on their own.
  - One mother said, "He couldn't feed himself at the time, I'm like "Oh my God, how's he gonna eat at lunch time, are they gonna feed him, what are they gonna do"…they didn't tell us that in the preschool program they stay in their classroom for lunch."
  - Another mother said: "[Getting] parent's involvement or help was really nice…but if I hadn't know anybody, I would have been 'up the creek.' I would have probably just taken him to the regular [public school] because that's what they…tend to encourage you to [do].

3) The role of the occupational therapist is viewed as dynamic, shifting in response to the needs of the child, the family, and the system.

- OT is equally important to families in EI and ECSE
- Benefits of OT in EI for child (developmental skills) and parents (help to adjust to disability and teaching techniques)
- Role of OT shifted as developmental needs of child changed…moved to higher level skills, goals, independence and functions…moved beyond home and family to community (inclusion) and school/ECSE classroom
- OT also met needs of teacher and other students…addressed skills necessary in classroom, modeled techniques, showed other students skills and how to help child with disabilities be included.
  - One mother said: "It's tending to shift some now, I mean, they're not so much doing the basics as they were earlier because he's met those milestones." (Lisa)
  - Another mother recognized a shift in OT services for her daughter. She described how in EI the primary role of the OT was feeding and respite for her. In ECSE, the OT initially worked on feeding, almost exclusively. She then recognized a shift in the focus of OT the second year her daughter was in ECSE: "Now that has changed…now the OT is actually working on her fine motor and adaptive skills. Now we're going into a new page with OT where she will be getting more typical…OT services." (Courtney)

4) Communication, involvement, and relationships are intimately related.

- Level of communication between parent and OT define the relationship
- Parents miss the positive relationship, involvement, and communication with the OT in EI (had a sense of who the OT was).
- Parents want frequent communication…therapy updates, quick notes about how the therapy is progressing
- Communication is the key to establishing positive relationships with OT and feeling involved in the therapeutic process.

    - One mother recounted her relationship with the first OT in ECSE: "I think she was a rare breed…I felt like I knew her and I felt like I could approach her so much more than any of the ones I've had since then…she spoiled me…I would get a note from her every time she saw him and that was wonderful…she would write in his communication book." (Wanda)
- Means of communication not as important as frequency of communication.
- As involvement in OT lessened from EI, communication with OT became more important (in ECSE). (substituted communication for involvement).
- Parents who didn't have open line of communication with OT felt alienated from the therapy process.
    - One mother explained: "There's not as much communication just because we [don't see them] as often. We don't get many notes in the notebook unless we specifically ask…I've met her once and Kevin's met her twice." (Lisa).
    - Another mother said: "I don't hear from her [OT]; she doesn't let me know what's going on or anything like that…I don't see her regularly or hear from her regularly. There's just not enough…I think there should be more communication." (Kathy).

Appendix J

Preliminary Participant Interview Evaluation

- Were there any questions you felt were unnecessary or repetitive?
- Were there any questions that made you feel particularly uncomfortable?
- Did any of the questions appear unclear, leading, or biased in any way?
- Were any questions offensive to you in any way?
- Did you feel sufficiently comfortable to respond honestly to the questions asked?
- Did you feel the length of the interview was a reasonable length?
- Were you able to express the information that you wanted to share about your experiences with early intervention and early childhood special education?
- Did you have difficulty with understanding any of the terms used?
- Was there any time in the interview that you felt the researcher was not respectful?
- Did you have time to talk about everything you felt was important?
- Did the researcher portray a relaxed style, making you more relaxed?
- Please comment on the researchers interview style:
- Please provide any additional comments or suggestions you would like to offer regarding the interview.

Appendix K

Auditor's Report

Audit Report for:

Parent Perceptions of Occupational Therapy in Early Childhood Special Education Programs Following Transition from Early Intervention Programs,
A Qualitative Research study conducted by Anita Wyrick, OTR/L

Prepared by Dr. Al Copolillo

February 17, 2003

The purpose of the study was to explore parent perceptions of occupational therapy services in early childhood special education programs following transition from early intervention programs and how these perceptions change over time.

Initial, guiding questions that shaped the study were:

- How do parents of children who formerly received early intervention services and who currently receive early childhood special education services view the role and benefits of occupational therapy in their child's preschool program?
- How do parents conceptualize the differences between service delivery of occupational therapy in early intervention and early childhood special education?
- How do parents describe the type and extent of communication with their child's occupational therapist at school?
    - How has this changed from that of early intervention?
    - How do parents describe the effectiveness and their level of satisfaction with this communication in comparison to the effectiveness and satisfaction with the communication they had with their child's OT in early intervention?
- How do parents describe the type and extent of their involvement with their child's occupational therapist at school?
    - How has this changed from that of early intervention?

- In what ways can occupational therapists help make the transition process flow smoothly for parents and children transitioning from early intervention to early childhood education?

Proposed qualitative research methods for data collection and analysis consisted of:

- Purposive sampling of six to ten parents of students with disabilities.
- In-depth, semi-structured, face to face interviewing of participants
- Transcribing of the audio-taped interviews.
- Extensive field note taking, written in journal or log format.
- Use of coding, categorizing, and theme-building strategies
- Identification of low-inference and high-inference interpretations from the data
- Content, inductive, and cross case analyses of verbatim transcripts

A primary focus of the qualitative research procedure is determining trustworthiness. It is similar in purpose to demonstrating content and construct validity and reliability in quantitative research but is a much different process. The process of ensuring trustworthiness in qualitative studies is one in which indications of credibility, confirmability, dependability, and transferability of the data are examined and reviewed. Lincoln and Guba (1985) describe this process in Naturalistic Inquiry. One way to determine trustworthiness is by conducting an external audit. External auditors possess methodological sophistication in qualitative design; have minimal substantive knowledge about the subject matter of the study, and have no personal interest in the study or its outcome.

The audit of ***Parent Perceptions of Occupational Therapy in Early Childhood Special Education Programs Following Transition from Early Intervention Programs*** began with reading a brief review of the study, its purpose, and the guiding research questions designed for the focus groups. It progressed from there to a systematic review of four cases, Wanda, Katie, Kevin and Lisa, and Courtney and review of samples of the remaining cases. The audit consisted of:

1. complete review of each audiotape.
2. reading and reviewing of each complete transcript
3. reading and reviewing of the initial, second, final, and revised final categories for each complete transcript read.
4. review of samples of each of the three remaining cases
5. review of peer debriefing notes
6. review of hand-written cross case analyses
7. review of low and high inferences
8. reading of Chapter V: Discussion

Confirmability

When the findings are drawn directly from the data and not from personal bias, assumptions, or a priori expectations and when the inferences drawn are logical, the findings are "confirmable". The transcripts are verbatim and reflect what was heard on the audiotapes and videotapes. The researcher provided a self-as-instrument statement in which she described potential biases and plans to minimize them. The field notes, especially the low level and high level inferences describe a process of deriving themes and assertions from categories. Coding of the data was accurate and specific. The study's strength also derives from clear description of the progression from codes to categories to inferences to themes by way of a detailed cross case analysis.

Dependability

Determining the dependability of the findings includes examining factors that indicate instability and factors of phenomenal or design-induced change in the data. In other words, were the methodological decisions and shifts appropriate? The data analysis provides good support for decisions drawn and shifts in the method of collapsing and managing the data into conceptual categories.

Credibility

Credibility refers to the process by which the researcher increases the likelihood that the participants are described accurately. Credibility is enhanced through demonstration of prolonged engagement, persistent observation, triangulation of data, peer debriefing, negative case analysis, referential adequacy (checking new data with archived "raw" data), and member checking. Many of these were completed effectively. The researcher continued to gather data and conduct member checks until the data was saturated. The researcher thoroughly discussed and reviewed data with peers and advisors. There were both negative and positive views expressed in a variety of themes and confirmations of findings from one transcript were verified with other transcripts through a detailed cross case analysis. The high level inferences were logical, derived nicely from the low level inferences, and the researcher nicely demonstrated the connection between inferences and themes.

Transferability

The researcher has demonstrated, through use of a diverse group of parents of children with special needs and rich descriptions of the characteristics of the participants that the data is transferable.

Audit Conclusions

Some of the many strengths of the study that are apparent from this audit are:

- The transcripts are verbatim. Information in the transcripts directly matches the audio-tapes.
- The field-notes reflect the primary researcher's involvement in discussion with peers and advisors about the content and meaning of the data.
- The researcher includes a self-as-instrument statement
- The themes are derived from the raw data.
- Low level and high level inferences are used to describe category content, and expand or collapse categories. The researcher uses the inference making process to move away from the raw data and develop more extensive interpretations. This is a progression from the three iterations of the analysis.
- Conclusions the researcher has derived from the cross case analyses are logical and develop appropriately into the main themes of the study.

Overall, the researcher has done a good job at following standard qualitative research methods to complete the study. What I gather from examining the process is that there was an initial question as to whether parents of children with special needs perceive occupational therapists in early childhood special education as providing intervention that is as effective and satisfying to them and their children as do occupational therapists in early intervention. Therefore, the researcher designed an interview protocol that probed parents to describe the best and worst of early intervention and early childhood special education experiences with occupational therapy practitioners. In the process, the researcher identified transition from one system to the other as a major challenge to parents. Parents also recognized the complexity and multiplicity of the occupational therapy practitioner role in ECSE and had varying experiences of adjustment to and comfort with the OT's communication skills, use of interventions, and interest in involving the parents in the therapeutic process. I detect no blatant methodological errors. The researcher has drawn conclusions directly from the data and has successfully demonstrated the trustworthiness of the data.

Al Copolillo, Ph.D., OTR/L
Assistant Professor

Vita

Anita Wyrick was born in New Orleans, Louisiana. She is married to Tony Wyrick. Together they have two children and have resided in St. Bernard Louisiana, Brunswick Ohio, Hertford North Carolina, Greenville North Carolina, and are now residents of Chesapeake Virginia.

Anita is currently a graduate student at Virginia Commonwealth University. She graduated with honors from P.G.T. Beauregard High School, St. Bernard, Louisiana in 1984. She received her undergraduate degree in Occupational Therapy in 1994 from East Carolina University in Greenville, North Carolina. In addition, she has also attended The University of New Orleans and The College of the Albemarle.

Anita is currently employed as an occupational therapist by Chesapeake Public Schools in Chesapeake Virginia. She has held such positions as evaluating occupational therapist for ECSE intake, Occupational and Physical Therapy Department Chairperson, and currently staff occupational therapist.