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Finding Childcare for the Disabled Child: The Process and Decisions Through the Primary
Caregiver's Lens

A Dissertation

Submitted to the Faculty of
Antioch University Seattle
Seattle, WA

In Partial Fulfillment
of the Requirements of the Degree
Doctor of Psychology

By
Misty D. Torres
2015

Finding Childcare for the Disabled Child: The Process and Decisions Through the Primary
Caregiver's Lens

This dissertation, by Misty D. Torres, has
been approved by the Committee Members signed below
who recommend that it be accepted by the faculty of the
Antioch University Seattle at Seattle, WA in partial fulfillment
of requirements for the degree of

DOCTOR OF PSYCHOLOGY

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Abstract

Childcare for the Disabled Child: The Process and Decisions Through the Primary Caregiver's Lens

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Seattle, WA

In this qualitative, Grounded Theory study, the researcher examined the process that primary caregivers go through when selecting a childcare placement for children who have special needs. Data were collected through participant interviews with primary caregivers ($n=10$) who responded to recruitment notices posted on (1) listservs by organizations directly affiliated with early intervention and child care services; (2) local Internet classified sites; and (3) through word of mouth. The research demonstrated that caregivers who learned of their child's disability in a prenatal diagnosis or prior to an adoption identified with having a greater sense of choice and control over their circumstances, and had more confidence in their ability to make competent, informed decisions regarding their child's needs than caregivers unaware prenatally of a diagnosis. The same was true for parents who had a primary support system in a spouse or significant other, thereby offering additional options over those available to a single parent. Second, due to poor provider training and education with special needs populations, caregivers were more likely to keep their child in the home and work around whatever financial hardship may result. Third, caring for a disabled child is an emotional paradox that is difficult, yet rewarding, and it is the unconditional love that caregivers have for their children that drives them to give tirelessly against the odds. Based upon the data, recommendations for future practice include a community model in which individual and/or family therapy is coupled with a strong

referral base that places the family into contact with relevant early intervention resources within the community. By working closely with the family and helping them to connect with organizations and professionals in their community, the therapist can empower the family by way of resources, psychoeducation, and support. The electronic version of this dissertation is at OhioLink ETD Center, www.ohiolink.edu/etd

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Introduction

Definitions

For the purpose of this study, the following definitions will apply:

1. *Childcare programs* shall be defined as any childcare center that is (1) licensed under Chapter 170-295 WAC, Minimum licensing requirements for childcare centers, or, Chapter 170-296 WAC, Licensed family home child care standards, and (2) whose enrollment consists of children who are either non-special needs, special-needs, or a combination of the two.

2. *Preschool programs* shall be defined as any preschool program (1) offering primarily educational programming for no more than four hours per day, and (2) whose enrollment consists of children that are either non-special needs, special-needs, or a combination of the two.

3. *Primary caregiver* shall be defined as any individual who (1) has legal decision-making power over the minor child, and (2) provides for the majority of the minor child's basic needs, nurturing, and support.

4. *Integrated programs* shall be defined as any program where the environment is inclusive of both children having special needs and typically developing children. Such an environment shall award all children the opportunity to learn, play, eat, and socialize with other children in their classroom, free of discrimination based on any known or perceived disability. Such an environment shall not prohibit childcare providers from having multiple classrooms based on the ages of the children enrolled in the childcare program.

Background

The process of selecting a childcare or preschool program is one important decision that parents make during the early years of their child's life. For many children, it is within these environments that social skills begin to develop, a sense of identity is formed, and simple rules

about everyday life are learned. With such critical developmental processes taking place, one can easily understand why parents place such a great deal of emphasis on locating a qualified childcare provider or preschool program to meet their children's learning needs.

As the child leaves the comfort of his/her home, and enters into a new environment, with new people, new expectations and new rules, parents may be concerned with such things as the child's social adaptation, ability to make friends, and participate in activities; the child's ability to maintain healthy nutrition by eating meals and snacks in a new environment; whether the child will receive the appropriate amount of time, attention, and supervision they require; the caregiver and/or teacher's level of attentiveness and patience with the child; and the type and number of experiences offered that support learning by the child. When a child has special needs, concerns such as these become all the more salient, because chronological age versus developmental age, and the child's unique individual needs, create a challenging context in which childcare and/or preschool will occur.

Bronfenbrenner's (1977) Ecological Systems Theory proposed that child development is influenced by a number of nested, interrelated systems that affect the child both directly and indirectly. These systems include the microsystem, or environment in which the child has direct contact (i.e., family home, childcare settings, classrooms, etc.); the mesosystem, or the interplay between two microsystems (i.e., the interaction between the family and the school system); the exosystem, which includes outside environments in which the child is not a direct participant, but is impacted by the environment (i.e., the parent's place of employment); and the macrosystem, which is comprised of social, cultural, and political factors. In this research dissertation, how each subsystem of this ecological model has influenced the decisions of the participants as they

made them regarding childcare and preschool for their disabled child will be articulated/discussed.

The topic of special-needs childcare and preschool is one that includes many facets that should not be overlooked when studying this important service to children. For example, a review of childhood diagnosis, Federal and State disability law, and early learning environments, is essential to the complex, multifaceted world of childcare and preschool for the disabled child.

There is a growing body of research pertaining to special-needs children and early childhood education. Federal laws such as the Individual with Disabilities Education Act (IDEA) (1990) and Section 504 of the Rehabilitation Act of 1973 have made it illegal to discriminate against children based on any known or perceived disability and have required states to proactively identify children at risk so that early intervention services may be offered. In the wake of Section 504 and IDEA there have been numerous research studies on early screening and intervention, inclusive childcare settings, and parental satisfaction with early intervention services. Individually these studies lend a great deal of information to different sub-topics in special needs early education and collectively they have the potential to provide a great deal of information into a multi-faceted, complex process that primary caregivers go through when selecting an early education program for their disabled child.

In this study, the researcher sought to understand the process that primary caregivers go through when selecting a childcare or preschool placement for their disabled child as well as factors that influenced their behavior and how these factors ultimately align to help shape the primary caregiver's decision. Looking through their parental lens, this research gives voice to the primary caregivers of special-needs children, faced with a monumental decision that few psychologists currently understand.

Literature Review

Childhood Disorders

Disorders that are first diagnosed in infancy and childhood include such things as Mental Retardation, Learning Disorders, Motor Skills Disorder, Communication Disorders, Pervasive Developmental Disorders, and Attention-Deficit and Disruptive Behavior Disorders. According to prevalence rates in The American Psychiatric Association's (2004) *Diagnostic and Statistical Manual of Mental Disorders*, Fourth Edition, Text Revision (DSM-IV-TR), the three most common childhood disorders are Communication Disorders which occur in 10%-15% of children; Learning Disorders which range from 2%-10% depending on the nature of ascertainment and the definitions applied; and Attention-Deficit and Disruptive Behavior Disorders which range from 1% to 16% depending upon the population and nature of ascertainment.

Communication disorders. The acquisition of language is a fascinating, complex process: the ability to mimic sounds will, eventually, turn into intelligible words for most typical developing children. Language can be broken down into five major subsystems: phonology, or the system of sounds and the rules of combining those sounds to make words; semantics, or the meaning of words and sentences; morphology, the system for modifying word meanings; syntax, the rules for organizing words into sentences; and pragmatics, the set of rules that govern the social use of language (DeHart, Sroufe, & Cooper, 2004). These subsystems are what comprise the skills necessary to produce language (i.e., productive skills). Another, important component of language development is that of receptive skills, or the skills used to listen and understand what other people are saying.

The age at which children acquire language, and the rate at which it grows, can vary among children. While most children start to use protowords, or vocalizations that seem to have consistent meaning for a child, between 10 and 12 months (DeHart et al., 2004), and then proceed to using first words shortly after their first birthday, some children acquire language sooner, while others experience a language delay. According to the American Speech-Language-Hearing Association, it is estimated that 24.1% of children in public schools receiving special education services have communication disorders (Barkoukis, Reiss, & Dombeck, 2008). While language delays can present in varying degrees across children, there are four major classifications as outlined in the DSM-IV. These are: Expressive Language Disorder, Mixed Receptive-Expressive Language Disorder, Phonological Disorder, and Stuttering.

Expressive Language Disorder is a Communication Disorder that refers to impairment in verbal expression. It is the most prevalent of all the communication disorders with a rate of 10% to 15% in children under age three, and 3% to 7% in school-aged children. The difficulties in verbal expression can include such things as delayed speech, limited vocabulary, and difficulty forming complex sentences. These difficulties can either be acquired from a significant medical event, or they can be a result of the developmental language process in that particular child (American Psychiatric Association, 2004).

Mixed Receptive-Expressive Language Disorder refers to impairment in both the expressive and receptive language. Not only are there difficulties in the verbal expression of words, there are marked difficulties in understanding words, sentences, and in the discrimination of sounds. It is estimated that 5% of preschool children and 3% of school-age children have Mixed Receptive-Expressive Language Disorder (American Psychiatric Association, 2004). As

in Expressive Language Disorder, Mixed Receptive-Expressive Disorder can either be acquired from a significant medical event, or it can be developmental.

Phonological Disorder is a marked impairment in the ability to produce speech sounds correctly. It can include such things as omissions of sounds, replacing the correct word with an incorrect word, or vowel distortions. It is estimated that 3% of preschool children have Phonological Disorder (American Psychiatric Association, 2004) and in 2006 almost 91% of speech-language pathologist indicated they served children with phonological disorders (American Speech-Language-Hearing Association, 2008).

Stuttering is a disorder that affects approximately 1% of prepubertal children and .8% of adolescents. It is marked by an abnormal fluency of speech that may include such things as word repetition, prolonged sounds, or the inappropriate use of pauses within a word. Age of onset is typically between 2 and 7 years with the highest incidence between a child's second and fourth birthday, affecting 4% to 5% of the population (American Speech-Language-Hearing Association, 2008).

Learning disorders. Learning Disorders (LD) are disorders in reading, mathematics, or written expression that are diagnosed when an individual's achievement is substantially below that which is expected based on his/her age, schooling, or level of intelligence (American Psychiatric Association, 2004). It is estimated that 2.4 million (41%) children who receive special education through the Individuals with Disabilities Education Act (IDEA) are diagnosed with LD (U.S. Department of Education, 2010). The associated features of Learning Disorders go beyond academic concerns within the classroom, and include such things as low self-esteem, deficits in social skills, and a school dropout rate at nearly 40% for children or adolescents with Learning Disorders (American Psychiatric Association, 2004).

Reading Disorder is a Learning Disorder that affects approximately 4% of school-age children, and it is estimated that between 60% and 80% of those diagnosed are males. It is marked by reading achievement in accuracy, speed, or comprehension that is substantially below the expected performance based on the age, education, or intelligence level of the individual; the reading difficulties significantly interfere with academic achievement or daily living; and, reading difficulties exceed those generally associated with a sensory deficit (American Psychiatric Association, 2004). While separate in their own diagnostic criterion, there is evidence to suggest that reading disorder has high comorbidity with Attention Deficit Hyperactivity Disorder (ADHD), especially among boys. For example, in a 2010 study examining the incidence of reading disorder among children identified as having ADHD and those without, researchers found that of the 5,718 children included in the study, 508 children had a reading disability, 75% of which were boys. Within the cohort of children who did not have a comorbid diagnosis of ADHD, the reading disorder rate was 14.5% for boys and 7.7% for girls. For the cohort of children who did have a comorbid diagnosis of ADHD, the reading disorder rate was 51% for boys and 46.7% for girls (Yoshimasu et al., 2010).

Mathematics Disorder affects approximately 1% of school-age children and is commonly found in combination with Reading Disorder or Disorder of Written Expression. It is marked by mathematical achievement in calculation or reasoning that is substantially below the expected range based on the individual's age, education, or level of intelligence; a disturbance in mathematics that significantly interferes with academic achievement or daily living; and, mathematic difficulties exceeding those associated with a sensory deficit (American Psychiatric Association, 2004).

Disorder of Written Expression is writing skills that are substantially the expected range based on the individual's age, education or level of intelligence. Similar to Reading and Mathematics Disorder, the disturbance in written expression must substantially interfere with academic achievement or daily living, and the difficulties must exceed those generally associated with a sensory deficit if one is present. Disorder of Written Expression is seldom diagnosed before first grade, although difficulties with poor handwriting and copying ability may appear at an earlier age (American Psychiatric Association, 2004).

Attention-deficit and disruptive behavior disorders. Attention-Deficit/Hyperactivity Disorder affects approximately 3%-7% of school-age children and is marked by a persistent pattern of inattention and hyperactivity; the symptoms must be present in at least two settings and must be present before age 7; symptoms interfere with developmentally appropriate social, academic, or occupational functioning (American Psychiatric Association, 2004). Recent data may suggest the incidence rate of ADHD is on the rise. For example, in the most recent 2011 "National Survey on Children's Health" administered by the Center for Disease Control, more than 1 in 10 (11%) school-aged children in the US had received a diagnosis of ADHD. Historically, this same survey found a 7.8% incidence rate in 2003 and a 9.5% rate in 2007 (Visser et al., 2013). The most common ADHD diagnosis is ADHD combined type and includes inattention, impulsivity, and hyperactivity symptoms (Daly, Cohen, Carpenter, & Brown, 2009). It is typically not diagnosed prior to age 4 or 5 because young children are typically not required to sustain attention for prolonged periods of time; however, younger children may present with excessive movement and be difficult to contain. These children have trouble with maintaining attention, may appear careless and hurried, may seem restless and fidgety, and they may produce sloppy, incomplete, or superficial school work (DeHart et al., 2004).

Conduct Disorder affects approximately 1% to 10% of children and is more commonly diagnosed in males than in females (American Psychiatric Association, 2004). Conduct Disorder can either be Childhood-Onset Type (onset prior to age 10 years) or Adolescent-Onset Type (onset after 10 years of age). Life-course-persistent conduct disorder is a conduct disorder that begins early, is stable across the childhood years, and predicts problems in adulthood; Adolescent-limited conduct disorder is a conduct disorder that first appears in adolescence and does not predict problems in adulthood (DeHart et al., 2004). It is marked by a repetitive pattern of behavior that violates the basic rights of others; disruptive behavior that causes clinically significant impairment in social, academic, or occupational functioning (American Psychiatric Association, 2004). It is associated with little empathy towards others, lack of appropriate feelings of guilt or remorse, early onset of sexual behavior, drinking, smoking, and other risk-taking behaviors. Conduct disorder is one of the most frequent diagnoses given to children who are referred to mental health centers and is among the most persistent (DeHart et al., 2004).

Oppositional Defiant Disorder affects approximately 2% to 16% of children and adolescents and is more common in males prior to puberty, with equal rates between male and female following puberty (American Psychiatric Association, 2004). In preschool aged males, it is associated with problems in temperament and high motor activity. Low self-esteem, mood lability, alcohol use, and parent/teacher conflicts are associated with older school-aged children with Oppositional Defiant Disorder (American Psychiatric Association, 2004). It is marked by negative, hostile or defiant behavior that lasts a minimum of six months; the behavior causes impairment in social, academic, or occupational functioning that is clinically significant; and the behaviors do not occur during a Psychotic or Mood Disorder (American Psychiatric Association, 2004).

Pervasive developmental disorders. Although less prevalent than Communication, Learning, and Disruptive Behavior Disorders, Pervasive Developmental Disorders such as Autism are equally important to discuss in the context of this study. Autistic Disorder is a developmental disorder that is marked by abnormally impaired development in social interaction and communication, accompanied by a restricted repertoire of activity and interests (American Psychiatric Association, 2004). The “autistic triad,” or three clusters of symptoms that must be present in early development for an Autism diagnosis to be given include at least two symptoms of qualitative impairment in social interaction (i.e., failure to develop peer relationships or lack of shared enjoyment); at least one symptom indicating qualitative impairment in communication (i.e., delays in spoken language or repetitive use of language); at least one symptom indicating restricted, repetitive, and stereotyped patterns of behavior, interests, and/or activities (Campbell, Segall, & Dommestrup, 2009).

Autism spectrum disorder is a range of related pervasive developmental disorders with overlapping symptoms and varying severity. The symptoms of Autism are generally present by the age of 3, and it is estimated that 1 in 88 children have been identified with an autism spectrum disorder by the age of 8 (U.S. Department of Health and Human Services, 2012). According to the 2012 report on the prevalence of Autism Spectrum Disorder, the Center for Disease Control, Autism is almost five times more common in boys than among girls, with 1 in 54 boys being diagnosed with Autism as compared to 1 in 252 girls. This same report also found a 78% increase in the diagnosis of ASD between the years of 2002 and 2008.

Early Screening

Early screening and intervention are believed to be important, if not essential, factors in fostering healthy development in a child experiencing developmental delays. The American

Academy of Pediatrics (AAP) (2006) calls early identification of developmental disorders “critical to the well-being of children and their families” (p. 1). Furthermore, the AAP’s practice guidelines for “developmental surveillance” places emphasis on the importance of early detection and calls upon pediatricians to conduct routine surveillance at every well-child preventative care visit, with concerns being promptly addressed with standardized developmental screenings. The guidelines go on to suggest that additional screening tests be administered at the 9, 18, and 30 month visits.

While early screening is generally believed to be important for future prognosis, there are differing opinions on who is best qualified to perform this service, and there are substantial discrepancies between the number of children who are estimated to have disabilities and those who are detected through early screening and intervention. For example, Branson, Vigil, and Bingham (2008) cite a prevalence rate of 12% to 16% of children ages birth to eight have a developmental disability, and only 1.8% of children ages birth to 2 are receiving early intervention services. The number is slightly higher in the three to five age ranges, with 5% of children receiving early intervention services. One possible reason for the low rate of early detection is the lack of consensus about who should provide early screenings and a corresponding policy to oversee such services. Potential screeners range from family primary-care physicians or pediatricians, to community child care providers, as both have frequent contact with young children and have relationships with their families.

Abcd project. An example model of early screening by primary care physicians can be seen in The North Carolina Assuring Better Child Health and Development (ABCD) Project, which began as a formal pilot for developmental screening and surveillance as an element of preventative care for children. The ABCD model is one in which the primary care physicians are

thought to be the most well informed professional with whom families have regular contact during the first five years of a child's life, and are, therefore, the most likely candidate to perform early screening and developmental monitoring (Earls & Hay, 2006). Well-child check-ups are a very important element of routine childcare during the first few years of life, and for many children, the family pediatrician or primary care physician begins performing well-child check-ups beginning on the fifth day of life and continues these routine examinations at regular intervals for the first 3-5 years.

When the ABCD Project began in 2000, North Carolina was among four states that received a grant for the purpose of creating and implementing a statewide system that would improve the delivery and financing of child development services. The comprehensive model was built on a 2-tiered approach that included (1) a best practice model for the early screening and surveillance of developmental and behavioral symptoms within a primary care practice; and (2) state leadership by a group of key representatives who were capable of making policy change. At the time of the project's conception, it was estimated that between 8% and 13% of the North Carolina's population between birth to 3 qualified for early intervention services, but only 2.6% were being served (Earls & Hay, 2006).

Before implementing the ABCD Project in a primary care practice, physicians and staff were tasked with selecting a screening process that was compatible with a busy schedule; satisfying to parents; required minimal staff; was fairly inexpensive; and that optimized early identification of children at risk. Parent-completed tools such as the Ages and Stages Questionnaire, Parents Evaluation of Developmental Status, and the Infant Developmental Inventory were seen as the best option, as they met the above requirements and they engaged the

parents in collaboration with the provider while viewing the parent as the expert on their child (Earls & Hay, 2006).

Since the project began in 2000, the number of infants and children who are screened during well-child visits is estimated at greater than 70 percent, and as a result, multiple healthcare organizations in North Carolina have revised their policy for early screening and surveillance. For example, in 2003, the Division of Public Health directed local health departments to use developmental screening tools in community nursing and well-child clinics. In 2004, the Division of Medical Assistance required standardized developmental screening including mental, emotional, and behavioral at 6, 12, 18, or 24 months and 3, 4, and 5 years of age (Earls & Hay, 2006).

Despite the fact that the ABCD Project appears to be a promising model for screening by primary care physicians, Branson et al. (2008) suggested that primary care physicians are not the best suited professionals to provide early screening due to inadequate reimbursements, lack of time, and limited staff resources to conduct screenings. Instead, Branson et al. (2008) proposed that community childcare providers are ideal service providers to conduct early screening and detection of developmental delays for multiple reasons:

(a) increasing numbers of infants and toddlers spend time in community childcare settings, (b) childcare providers receive training in typical child development and are encouraged by their professional organizations to screen child development, (c) childcare providers have multiple opportunities to monitor child development when the child is present in the daycare setting on a daily basis, and (d) there is the possibility of establishing a collaborative relationship among community childcare settings and early intervention and school district special education programs to identify and serve children with developmental delays. (p. 526)

Branson et al. (2008) proposed a developmental surveillance model that is based upon the recommendations of AAP (2006). In this model all children are screened at the time of enrollment using the Ages and Stages Questionnaire (ASQ). Children are screened at regular

intervals between the ages of one and five years of age, and all children are screened at ages 18 and 24 months using the Modified Checklist of Autism in Toddlers (M-CHAT). Any child who fails the periodic developmental screening or the M-CHAT is referred for developmental evaluation.

As with primary care physicians, there are likely to be concerns with the ability of childcare providers to adequately screen for developmental delays. As Branson et al. (2008) pointed out, childcare providers can experience difficulties in several areas: First, childcare providers may struggle with finding the appropriate language when talking with parents about their child's developmental differences; second, there is a risk of misdiagnosis since differential diagnosis can be difficult; and third, misdiagnosis can lead to inappropriate labeling and a lowering of expectations for the child, that can inadvertently have a negative impact on the child's developmental course. Albeit not suggested by Branson et al. (2008), it is possible that all three of these concerns could be tied to the community childcare provider's level of specialized education and training in mental health. One cannot argue that community childcare providers spend a considerable amount of time with children as compared to other professionals such as primary care physicians or mental health professionals. On the other hand, one can easily argue the level of education and mental health training that many community childcare providers have, is far less than that of a primary care physician or mental health professionals such as psychologists and psychiatrists. That being said, community childcare providers have a unique opportunity to observe children for extended periods of time and as such, their observations are of great value and should be considered in conjunction with a full screening from a qualified mental health professional that is trained in assessment and diagnosis of childhood disorders.

Federal and State Disability Laws and Services

Once a delay has been identified, the task at hand turns to appropriate early intervention services to meet the child's distinct need(s). As such, one must consider Federal and State disability laws and how they apply. The Individuals with Disabilities Education Act (2004) IDEA and Section 504 of the Rehabilitation Act of 1973 are Federal disability laws that provide protection to disabled children by making it illegal to discriminate against any child with a known or perceived disability; requiring States to identify infants, toddlers, and children who are at risk; providing early intervention services and necessary equipment to aid disabled children in learning; and by setting the standards in which disabled children receive education. Although similar in many components, there are differences between IDEA and Section 504 such that not every disabled child will qualify for services under both.

Individuals With Disabilities Education Act. The Individuals with Disabilities Education ACT (IDEA) of 2004 is a United States Federal law that governs how states provide early intervention, special education and related services for more than 6.5 million children with disabilities (see Idea.ed.gov, 2012). Under IDEA, the term child with a disability is defined as a child “with intellectual disabilities, hearing impairments (including deafness), speech or language impairments, visual impairments (including blindness), serious emotional disturbance, orthopedic impairments, autism, traumatic brain injury, other health impairments, or specific learning disabilities; and (ii) who, by reason thereof, needs special education and related services” (20 USC § 1401 (3) (A) (i)-(ii)).

In general, the provisions of IDEA provide for the following:

- Free Appropriate Public Education (FAPE) to all children with disabilities, including those who have been suspended or expelled from school (20 USC § 1412 (1)).
- FAPE that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment, and independent living school (20 USC § 1400 (d)).
- A goal of providing full educational opportunity to all children with disabilities and a detailed timetable for accomplishing that goal (20 USC § 1412(2)).
- The creation of an Individualized Education Plan (IEP) that is reviewed and revised for each child with a disability (20 USC § 1412(4)).
- The opportunity to learn in the Least Restrictive Environment (LRE), to the maximum extent appropriate. This clause provides that children should be giving the opportunity to learn in integrated settings, with children who are not disabled, and that disabled children should not be segregated into special classes, schools, or otherwise removed from the regular educational environment unless the nature or severity of the disability requires such to occur (20 USC § 1412(5)).
- Smooth transition into preschool programs for all children who receive services under Part C, and who will participate in preschool programs under Part C [Infants and Toddlers with Disabilities] as well. The transition must take place by the child's third birthday, and must include an IEP, or an Individualized Family Service Plan (IFSP) (20 USC § 1412(9)).

- Early intervention services which are designed to meet the developmental needs of an infant or toddler with a disability, as identified by the individualized family service plan team, in any 1 or more developmental area 20 USC § 1432 (4)).

Children under the age of three are addressed specifically in IDEA Part C, INFANTS AND TODDLERS WITH DISABILITIES. The term infant or toddler with a disability is defined as “an individual under 3 years of age who needs early intervention services because the individual (i) is experiencing developmental delays, as measured by appropriate diagnostic instruments and procedures in 1 or more of the areas of cognitive development, physical development, communication development, social or emotional development, and adaptive development; or (ii) has a diagnosed physical or mental condition that has a high probability of resulting in developmental delay” (20 USC § 1432 (5)(A)(i)-(ii)).

IDEA grants authority to the State to define ‘developmental delay’ for the purpose of identifying infants and toddlers with a disability who are in need of services under Part C. In Washington State, where this study was focused, the Early Support for Infants and Toddlers (ESIT) program, also known as Birth to 3, is the division within the Washington State Department of Early Learning that provides early intervention services for children ages birth to three, having disabilities or developmental delays.

Washington State Early Support for Infants and Toddlers. To be eligible for ESIT services, a child must have “a 25 percent delay or show a 1.5 standard deviation below his or her age in one or more of the developmental areas” (Washington State Department of Early Learning, 2010). These include such things as cognitive and physical development; communication; social or emotional development; or adaptive skills. A child may also be eligible

if he or she has a physical or mental condition such as Down Syndrome that is known to cause a delay in development (Washington State Department of Early Learning, 2010).

Children who are eligible for services through the Birth to 3 Program are assigned a family resource coordinator who, among other things, assists the family in developing an Individual Family Service Plan (IFSP); assists the child through the early intervention services he/she will receive; with the family's consent, works in conjunction with the school district to coordinate the child's evaluation for special education services; facilitates the transition out of the Birth to 3 program upon the child's third birthday; and assists the family with community resources if the child is not eligible for special education services (Washington State Department of Early Learning, 2010).

To be eligible for special education at age three, the school district must find that a child meets the requirements of Washington Administrative Code 392-172A-01035 Child with a disability or student eligible for special education.

A student eligible for special education means a student who has been evaluated and determined to need special education because of having a disability in one of the following eligibility categories: Intellectual disability, a hearing impairment (including deafness), a speech or language impairment, a visual impairment (including blindness), an emotional behavioral disability, an orthopedic impairment, autism, traumatic brain injury, other health impairment, a specific learning disability, deaf-blindness, multiple disabilities, or for students, three through eight, a developmental delay and who, because of the disability and adverse educational impact, has unique needs that cannot be addressed exclusively through education in general education classes with or without individual accommodations, and needs special education and related services.

WAC 392-172A901035 goes on to define a developmental delay as

A student three through eight who is experiencing developmental delays that adversely affect the student's educational performance in one or more of the following areas: Physical development, cognitive development, communication development, social or emotional development or adaptive development and who demonstrates a delay on a standardized norm referenced test, with a test-retest or split-half reliability of .80 that is at least: two standard deviations below the mean in one or more of the five developmental

areas; or one and one-half standard deviations below the mean in two or more of the five developmental areas.

Children who are eligible for special education at age three, and whose parents wish to utilize the service, transition out of the Birth to 3 Program, into the special education preschool where they receive an Individualized Education Program tailored to meet their distinct learning needs. Children who are not eligible for special education preschool will be referred for community services that the family may wish to utilize until the child reaches kindergarten age. To summarize, qualifying Washington State children are eligible for special needs services through ESIT when they are between the ages of birth to three. Once a child reaches the age of three, they exit from the ESIT program into the public school system and are then qualified to receive services through an Individualized Education Plan.

Section 504 of the Rehabilitation Act of 1973. Section 504 of the Rehabilitation Act of 1973 is a Federal law protecting individuals from discrimination based on any known or perceived disability.

No otherwise qualified individual with a disability in the United States, as defined in section 705(20) of this title, shall, solely by reason of her or his disability, be excluded from the participation in, be denied the benefits of, or be subjected to discrimination under any program or activity receiving Federal financial assistance (29 USC § 794 a).

Section 504 applies to any employer or organization that receives Federal assistance in any form. This includes, but is not limited to, entire corporations, partnerships, private organization, entire sole proprietorships, colleges, universities, local educational agencies, vocational education, and other school systems (29 USC § 794 b).

Section 504 defines a person as disabled if he or she “(i) has a physical or mental impairment which for such individual constitutes or results in a substantial impediment to employment; and (ii) can benefit in terms of an employment outcome from vocational

rehabilitation services provided pursuant to subchapter I, III, or VI of this chapter” (29 USC § 705 (20) (A) (i)-(ii)). It is important to note that not all children who qualify for services under Section 504 will qualify for services under IDEA. This is due to the fact that Section 504 has a broader definition of disability. The reverse, however, is generally true. Children who qualify for services under IDEA generally qualify for Section 504 services as well.

Anyone can refer a student for a Section 504 evaluation with the local school district; however, a family must give consent before the child is evaluated and before their first placement, provided the child is determined to be eligible for Section 504 services. Evaluations for Section 504 may include multiple measures, such as aptitude and achievement data, medical and psychological data, and social and cultural data. Similar to IDEA, Section 504 provides that disabled individuals have the opportunity for Free Appropriate Public Education (FAPE) in the Least Restrictive Environment (LRE). Unlike IDEA, Section 504 does not ensure that children will receive special education services that are designed to meet their unique learning needs, although they may. “Under Section 504, an ‘appropriate’ education means an education that is comparable to the education provided to students without disabilities” (Howey, 2012). Because the meaning of FAPE can vary by student, it is outlined in the student’s Section 504 plan that is specifically designed to meet his or her individual educational needs. In general, it can include education in regular classes, classroom aides, special education, or a combination of one or more of these services.

In addition, Wright and Wright (2008) pointed out two notable differences between Section 504 and IDEA. First, is the manner in which discipline issues are addressed under each service. Under Section 504, children who misbehave could be permanently expelled from school if the school decides the behavior is not a manifestation of the disability. In such a case, there is

no right to continued FAPE. On the other hand, children who receive services under IDEA have a right to FAPE even when expelled from school. Second, Section 504 lacks clearly established procedural safeguards such as prior written notice of any change to the Section 504 plan. IDEA, however, includes a detailed system of procedural safeguards that requires written notice and the right to an independent educational evaluation at public expense prior to any change in placement. Differences such as these are not highlighted to point out deficits in the services and protections available under Section 504, but rather, they are addressed here to inform the reader that parents need to be fully aware of how their children qualify for, and receive, disability services, as the protections and rights of children and their parents can differ between the two.

Early Learning Environments

There are a number of childcare and preschool options available to parents, including state-licensed childcare providers; kinship care; babysitters; private nannies; public preschools; and private preschools. While each option inevitably has its pros and cons, research is clear that high-quality early learning programs promote future academic success and occupational life skills, and that children who attend such programs benefit from increased cognitive, language, and social development (Barnett & Masse, 2007; U.S. Department of Health and Human Services, 2006; Reynolds, 1999; Temple & Reynolds, 2007). The National Institute of Child Health and Human Development's (NICHD), Study of Early Child Care and Youth Development (SECCYD), began in 1991, and is a longitudinal study that examined the short- and long-term relationships between childcare and children's development. The study followed more than 1,300 children beginning at one month of age through age 15. At age 1 month, 40 percent of the children lived in families defined as poor or near-poor; 85.5 percent had mothers who were married or partnered; 12.7 percent were defined at birth as black/non-Hispanic; 6.1

percent were Hispanic, and 4.8 percent were other minorities (U.S. Department of Health and Human Services, 2006).

Data were collected from 10 sites around the U.S. in four different phases: Phase I covered the period of time between 1 month and 3 years; Phase II, four years through first grade; Phase III covered first through six grades; and Phase IV, through ninth grade. Multiple measures were taken during each phase, including parent/teacher evaluations; academic transcripts; child's self-report; and researcher observation.

The features of child development that were measured included cognitive and language development; social behavior; emotional development and relationships with mothers; and health and physical growth.

In determining what constitutes quality childcare, researchers examined “regulable” features that included adult-to-child ratio, group size, and the training/education of the childcare provider. Features such as these are regulated by individual state laws that generally outline the minimum requirements that licensed childcare environments must meet. Many children in the NICHD study between infancy and age three were in childcare environments that did not meet the minimum guidelines. For example, at six months of age only 36% of children were in centers that meet the adult-to-child ratio; 56% were in centers where the caregiver meet the minimum guidelines for training; and 65% were in centers where the caregiver meet the minimum guidelines for education. At age 1½, 20% of children were in centers that met the adult-to-child ratio; 60% met the minimum guidelines for caregiver training; and 60% met the minimum guidelines for caregiver education encourage (U.S. Department of Health and Human Services, 2006). The study emphasizes that regulable features were important because children who attended centers that met the minimum guidelines had “slightly better school readiness and

language comprehension outcomes and fewer behavior problems at age 3 than did children in centers that did not meet the standards” (U.S. Department of Health and Human Services, 2006, p. 10).

Process features focused on the child’s day-to-day experience in the childcare including their social interactions with adults and other children, as well as the level of positive care giving experienced by the child. Positive care giving included such things as the caregiver’s positive attitude towards the child, positive physical contact between caregiver and child, and the caregiver’s tendency to read, tell stories, sing, praise, or encourage (U.S. Department of Health and Human Services, 2006).

An important measure in the study was that of *Family features*, which included such things as quality of the family environment, parental attitudes, and mother sensitivity. Family features were examined through repeated 2-hour visits to the children’s homes, written questionnaires, and observations of interactions between mothers and their children in pre-designed situations. When examining the relationship between family features and development:

One of the most important and consistent predictors of child cognitive and social development was the quality of the mother-child interactions. The more sensitive, responsive, attentive, and cognitively stimulating the mother was during observed interactions, the better the children’s outcomes. This result was the same when researchers examined attachment security, language development, pre-academic letter and number skills, and social behavior. (U.S. Department of Health and Human Services, 2006, p. 23)

Among the major findings, the U.S. Department of Health and Human Services (2006), found that:

- Children in higher quality non-maternal childcare had somewhat better language and cognitive development during the first 4½ years of life. (p. 1)

- Children who experienced higher quality childcare were somewhat more cooperative and compliant and slightly less aggressive and disobedient at 2 years and 3 years of age. (p. 13)
- Higher quality childcare predicted more positive interactions with other children at age 3 years. (p. 13)
- High quality child care also predicated greater school readiness at 4 ½ years of age, as reflected in standardization tests of literacy and number skills. (p. 12)
- The most important feature of quality for predicting cognitive and language development up to age 3 was the language used by the caregiver. More stimulation from the caregiver-asking questions, responding to vocalizations, and other forms of talking- was linked to somewhat better cognitive and language development. (p. 12)

As the researchers pointed out, it is important to keep in mind that the NICHD study occurred in naturally occurring patterns. Children were not assigned to a certain childcare, the researchers did not set the amount of time the children would spend in the childcare, and not all children entered the childcare settings at the same age. To that extent, the individual differences among children's development cannot be attributed as a direct effect of the childcare environment, but rather, they are associations.

Child parent centers study. In the federally funded Chicago Longitudinal Study, also known as the Child Parent Center (CPC) study, researchers examined the effects of an early, extensive childhood intervention program. The study was based on the assumptions that “development is optimized in rich, stable learning environments and when parents are involved in the process of learning” (Grau, Clements, Reynolds, & Niles, 2004, p.7.) Reynolds (1999) outlines four major goals of the study as follows:

- To document patterns of school performance and social competence throughout the school-age years, including their school achievement and attitudes, academic progress, and psychosocial development .(p. 1)
- To evaluate the effects of the Child-Parent Center and Expansion Program on child and youth development. Children and families had the opportunity to participate in this unique Head Start type early childhood intervention from ages 3 to 9 (preschool to third grade.)(p. 1)
- To identify and better understand the educational and psychosocial pathways through which the effects of early childhood experiences are manifested, and more generally, through which scholastic and behavioral development proceeds. (p. 1)
- To investigate the contributions to children's educational and social development of a variety of personal, family, school, and community factors, especially those that can be altered by program. (p. 1)

The sample for the study consisted of 1,539 at-risk children who were living in the most impoverished neighborhoods of Chicago. Preschool aged children , ages 3 or 4 accounted for 989 children in the study; 93% were African American; 90% were eligible for subsidized school lunch program; about one-half resided in single-parent families and in families in which parents were not employed full or part-time (Grau et al., 2004; Reynolds, 1999).

Children in the CPC classrooms received early intervention services from educators who had at least a bachelor's degree with certification in early childhood, as well as a variety of services for center staff including health screening, speech therapy, nursing, and meal services. Families worked in conjunction with the School-Community Representative who provided outreach services including resource mobilization, home visitation, and enrollment of children. The curriculum was focused on social-emotional development, academics, small groups, centers, individual work, and fieldtrips, and it included a unique component of parental involvement. Parental involvement was highly emphasized at CPC as an important component to early learning, so much so that parents were required to spend at least one-half day per week in the parent involvement program. This program included such things as volunteering in the classroom and school events, attending school outings, and participating in parent group activities with

other parents in the program and participating in supplemental educational trainings (Grau et al., 2004).

The instructional approach in CPC classrooms was measured by the teacher's self-report of how often they utilized various methods of instruction including large group activities, formal reading instruction, learning centers, fieldtrips, and child- and teacher-directed activities. Centers were classified as relatively high or low on two dimensions of preschool instruction: teacher-directed instructional activities and child initiated instructional activities. The use of direct instruction materials emphasizing phonics and pencil and paper activities were attributes of centers that rated high on teacher-directed activities, while centers that were rated low in teacher-directed activities used activity-based approaches or materials that emphasized the use of language in context (i.e., Peabody Language Development). Centers that rated high in child-initiated approaches reported using child-focused approaches such as learning centers, field trips, and child-initiated activities "often." Using these ratings, four instructional groups were formed: high teacher directed instructions and high child-initiated instruction; high teacher-directed education and low child-initiated instruction; low teacher-directed instruction and high child-initiated instruction; and low teacher-directed instruction and low child-initiated instruction (Grau et al., 2004).

School readiness skills in listening, early reading, and mathematics were measured at the start of kindergarten using the Iowa Test of Basic Skills (ITBS). Kindergarten achievement was measured using the word analysis and mathematics subtests of the ITBS. Testing consisted of 35 items that assessed pre-reading skills such as letter-sound recognition and rhyming, and 33 items measuring numbering, classification, and quantification (Grau et al., 2004).

According to Grau et al., (2004), the results of the school readiness and kindergarten achievement demonstrated that:

- School readiness was positively associated with a high teacher directed and high child initiated instructional emphasis, and negatively associated with a high teacher directed and low child initiated emphasis. (p. 16)
- Having two years of preschool as compared to one year was significantly related to greater school readiness, word analysis scores, and math achievement. (p. 16)
- Children attending full day kindergarten had significantly higher word analysis scores. (p. 16)
- Over 70 percent of children attended centers with medium to high levels of parent involvement as rated by teachers. (p. 15)
- Parent involvement was rated higher at centers that emphasized child initiated activities. (p. 15)

As both the NICHD and the Chicago Longitudinal Study demonstrate, increased cognitive, language, and social development are associated with quality early learning in childcare and preschool. Moreover, both studies demonstrate the added benefit and overall importance of parental involvement in a child's early education.

Method

Grounded Theory Introduction

Classic grounded theory was co-created in the 1960s by Barney Glaser and Anselm Strauss. In the early development of grounded theory, Glaser and Strauss examined the role of theory in sociology and defined the interrelated jobs of such theory as follows:

[to]Enable prediction and explanation of behavior; (2) to be useful in theoretical advance in sociology; (3) to be usable in practical applications-prediction and explanation should be able to give the practitioner understanding and some control of situations; to provide a perspective on behavior-a stance to be taken toward data; and to guide and provide a style of research on particular areas of behavior. (Glaser & Strauss, 1967, p. 3)

Grounded theory is held to four specific criteria: Relevance, fit, workability, and modifiability (Glaser, 1978). Relevance refers to the quality of the topic and the likelihood that it will be of particular interest. Fit refers to how well the concepts relate to the subject matter about which the participants were speaking. Workability relates to how well the grounded theory can be applied in different contexts or fields of studies. And lastly, modifiability refers to the ease with which grounded theory can be altered as new data become available.

Kelle (2005) describes grounded theory as a way to challenge the “hypothetico-deductive approach that demands the development of precise and clear cut theories or hypotheses before the data collection takes place.” Creswell (2007) described grounded theory as an intent to “move beyond description and generate or discover a theory, an abstract analytical schema of a process” (pp. 62-63) with the key idea that theory development does not come off the shelf, but rather is grounded in the process experienced by the participant.

Since its original conception, Glaser and Strauss have each continued to further advance the method, but each with differing views on the actual process. In 1978, Glaser’s *Theoretical Sensitivity* expanded on the grounded theory process as originally detailed in the combined works of Glaser and Strauss’ (1967) *Discovery of Grounded Theory: Strategies for Qualitative*

Research. The 1990, *Basics of Qualitative Research* co-authored by Strauss & Corbin offered a revised process for conducting grounded theory that Glaser (1992) argues is more than a different version of grounded theory, it's an entirely different method of qualitative research that results in a conceptual description rather than grounded theory (Walker & Myrick, 2006).

At first glance, the grounded theory process as outlined by Glaser or by Strauss & Corbin (1990) may seem similar in nature. In fact, one could argue they are similar and the differences are so minute the novice researcher may not be fully aware of how the two differ. After all, both include the use of outside literature and pre-knowledge of the subject area, data gathering with research participants, coding and abstraction of the data, and creation of a final theory. A closer look, however, will demonstrate that subtle differences at each step in the process are what create two very different processes for carrying out a grounded theory study. Among the more notable differences is the role of literature to the grounded theory study, the role of the research question, and the use of Axial coding.

While both forms of grounded theory seem to acknowledge that a researcher does not approach the research completely uninformed, due to personal experience and an overall general knowledge of various subject matters, they each hold the utility of the literature to different standards. Glaser's model (1978) suggests that any prior understanding of the research area should only focus on the subject in general and that prior readings should be widely inclusive of the subject matter at whole, rather than focused on specific areas within the subject. Such an approach will help to prevent any pre-conceived ideas of where the problem lies and keep the researcher open to various possibilities. In contrast, the Strauss model (1987) holds that the use of self and one's own personal experience, combined with a more specific approach of readings, can be used to formulate an early hypothesis.

A second notable difference is the role of the research question. Classic grounded theory process begins with a single, unstructured interview, meaning the researcher does not prepare a list of pre-defined questions he/she will ask of the participant. Instead, the researcher introduces the main research question, and participants are encouraged to respond freely about whatever comes to mind. While other methods allow for the researcher to steer the interview in the direction he/she hopes to study, classic grounded theory restricts the researcher from leading the interview and, instead, requires the researcher be attuned to two key analytical questions: What is the participant's main concern and how is he/she dealing with this concern? By allowing the data to take the lead, the researcher sets aside his/her agenda and allows for the creation of a theory that emerges from the data.

In contrast, Strauss and Corbin (1990) contend the research question should specify what phenomenon is to be studied. Using Strauss' method, the mere fact that the researcher is encouraged to pose questions specific to a particular area within the generalized topic is, in and of itself, driving the data in the area he/she wishes to go. It steers the participants to focus on the specific area of question, rather than allowing the participant to speak freely about what they feel is most important, and therefore it prematurely creates data to support a contrived core concern.

The third major difference is the process by which data analysis is carried out. At its conception (Glaser & Strauss, 1967), grounded theory consisted of two levels of coding: substantive and theoretical coding. Substantive coding was further broken down into two sub-phases: open and selective coding. Substantive coding is the process by which data are dissected, analyzed, and coded according to their content to describe the particular subject matter about which the participant is speaking. During open coding, codes are continually compared against one another to ensure all data is accounted for, new codes are created as they emerge, and

existing codes renamed when appropriate. It is within open coding that the core variable emerges. The core variable is the “main theme of what is happening in the data” (Glaser, 1978, p. 94). It is the concept most closely related to all other concepts, and it addresses the main concerns of all, or most of, the participants. Selective coding is the phase in which the researcher tests the relationship of all codes against the core variable to determine fit, relevance, modifiability, and workability.

The notion that “all is data” is essential to grounded theory and it allows for the dynamic relationship between the data and the researcher’s thoughts, assumptions, and emotions. The researcher is constantly invested in the data, continually analyzing and comparing new information to old. As thoughts, assumptions, emotions, or questions come to mind, the researcher captures the moment by the process of memo writing. Similar to participant interviews, memos are coded into conceptual categories that describe what the memo is about.

Strauss and Corbin (1990) have expanded upon the original structure for coding and included a third, intermediate, level with the coding process being labeled as Open coding, Axial coding and Selective coding (Walker & Myrick, 2006). Strauss and Corbin begin with a line-by-line analysis and creation of multiple codes but, unlike Glaser, Strauss and Corbin are also focused on the properties and dimension of each code during the initial open coding phase.

The use of Axial coding is an intermediate level of coding introduced by Strauss and Corbin (1990) that is not used by Glaser and is not directly comparable to any of Glaser’s coding phases. It is a phase in the coding process in which the fractured data from the open coding stage is put back together using a coding paradigm. The paradigm examines three aspects: the condition in which phenomenon occurs, the actions of people in response to phenomenon, and the consequence or result of said action (Strauss & Corbin, 1998; Walker & Myrick, 2006). In

response to this newfound level of coding, Glaser (1992) stated that Axial coding was “a very clear example of Strauss’ lack of scholarship in his entire book” (p. 61) and stated that connections between categories will actually emerge on their own if one codes only what is in the data (Walker & Myrick, 2006).

In the final stage of Strauss and Corbin’s (1990) Selective coding (not to be confused with Glaser’s sub-process of Selective coding), the analyst selects a core category and then codes/relates all other categories to the selected core. In Glaser’s (1978) final stage of Theoretical coding, the analyst conceptualizes how substantive codes may be related. With a core variable having previously emerged in the open coding phase, the researcher goes back through all of the previously coded data and codes for theoretical abstraction. The resulting theoretical codes integrate the core themes into a grounded theory that expresses the participant’s main concerns, and the ways in which they attempt to resolve the same. The codes are, according to Glaser, a way to “weave the fractured story back together again” (Glaser, 1978, p. 72). While Glaser’s stage of Theoretical coding could be described as similar to Strauss and Corbin’s Axial coding, the key difference is that Glaser’s model is not limited to the three considerations within the coding paradigm and it allows for a wider range of perspectives and hypotheses (Dey, 1999; Walker & Myrick, 2006).

Having outlined the key differences between Glaser vs. Strauss and Corbin, it is important to note this research study was carried out using the classic grounded theory of Barney Glaser. When the research study was initially considered, I expressed an overall interest in the areas of childcare and preschool for children who have a special need(s). I knew little about this topic and was seeking to understand what issue(s) were most important to the families who had experience in this area. Classic grounded theory was a natural method for this study, as

preconceived ideas and theories have no room in classic grounded theory, and the role of the researcher is to approach the subject unbiased, uninformed by the literature, and open to exploration of what the participants feel is the main concern(s). Staying true to such an approach will result in the emergence of a theory that is wholly grounded in the data. It is important to note, however, that in the case of a doctoral dissertation the criteria are different, as students must demonstrate their research is new knowledge and they must apply their scholarly expertise through a comprehensive literature review. To that extent, a preliminary literature review was completed, but staying true to the grounded theory process, the literature review was wide spread, there was no pre-conceived hypothesis, and the researcher relied upon the participants to guide the data.

Participants

This sample consisted of ten participants, all of whom were female, primary caregivers of a child with special needs. Inclusion criteria for participation in the study required that an individual be the primary caregiver as defined above, be currently looking for childcare or have looked for childcare in the past two years, and, self-report their child meets the following criteria: he or she (1) has a developmental disability that is likely to impact thinking, learning, or memory; (2) is between the ages of 0-4 yrs.; and (3) lives in Washington State.

Primary caregivers, as opposed to parents, were interviewed; for many children their primary caregiver may not be their biological or adopted parent. Grandparents, stepparents, legal guardians, and so forth are responsible for the health, safety, and well-being of thousands of children today, and the researcher did not want to exclude such important voices, should they wish to participate. The sample consisted of one legal guardian, one adoptive parent, and eight biological parents. The study was open to both parents if they wished to participate.

The primary caregiver's self-report of a developmental delay was used, as opposed to an official diagnosis, for two reasons: First, a child need not have an official diagnosis for a primary caregiver to be keenly aware their child has a special need that sets them apart from typical developing infants/toddlers. For the purpose of this study, the researcher was particularly interested in the primary caregiver's point of view concerning their child's special need, and how their point of view had shaped the process of finding qualified childcare for their child. Second, because many childhood disorders are not yet diagnosed in the 0-4 yr. age range, the researcher did not want to limit those children who had symptoms, yet no official diagnosis. .

The age range of the study was limited to 4 years because the researcher was particularly interested in children who are not yet enrolled in preschool and are not yet part of the public school system, that is, children who attend a regular, state-licensed, childcare program.

Washington State is the focus of the study because the researcher was particularly interested in local resources, policy, and law that relate to licensed childcare. A child's special need, age range, and area in which they live ultimately informs the choices available to Washington State's primary caregivers deciding which programs best meets their child's distinct learning needs.

Participants were recruited via one of the following methods: Listservs by organizations directly affiliated with early intervention and child care services; recruitment notices posted on local Internet classified sites; and word of mouth. Two participants responded to a recruitment notice on craigslist.com; one participant was recruited through the Washington State Birth to Three Program; four participants were recruited from the Washington State Child Care Resource and Referral Network; and two participants were recruited by word of mouth. The tenth

participant is the researcher, who also met criteria for the research study. As a thank-you gift for their participation in the study, participants received a \$10 Starbucks gift card.

Participants were screened via telephone to ensure they met criteria for inclusion in the study, and eligible participants were provided a copy of the Informed Consent via electronic mail. Participants were provided the researcher's email address and contact phone number in the event they had questions regarding the Informed Consent or the study itself. Upon return of the Informed Consent, follow up interviews were scheduled.

The Interview Process

Each participant underwent a single interview which took place in public meeting spaces chosen by the participant ($N = 4$), or via telephone for those participants who were not able to interview in person due to the high demands and hectic schedules of their responsibilities as primary caregiver for a child with special needs ($N = 5$). The final participant, the researcher, responded to the interview question in written format, reflecting upon her personal experience in this situation. In addition, the researcher reflected upon the memos that she wrote throughout the research process to examine those memos that related directly to her personal experience. Prior to the interviews, the researcher reviewed the Informed Consent with the participant, and participants were given the opportunity to ask questions regarding the purpose, nature, and intent of the research study. Participants were reminded that interviews would be recorded for the purpose of transcription, coding, and analysis.

Using the Grounded Theory (GT) approach to qualitative research, each interview commenced with a single question: "Please describe for me what it's like to be a primary caregiver of a child with special needs and the process you go through in trying to find a childcare program that best meets your child's distinct needs." Participants were directed to

answer the question in as much detail as they felt was relevant to the telling of their personal process. The researcher allowed participants to speak freely about whatever came to mind, rather than guide the participants through a specific line of questions that may or may not have been relevant. Glaser (1992) cautioned the researcher against the latter when he said, “Even when specific questions can be asked without forcing the data or its collection, the researcher never, never asks that question directly in interviews as this would preconceive the emergence of data” (p. 25).

Data Analysis

This study followed Glaser and the systematic processes of Classical Grounded Theory (CGT) with the following exceptions: First, the researcher conducted a preliminary literature review to ensure this research was original research for the purpose of writing a doctoral dissertation and to become well acquainted with the topics that comprised the study’s focus. Second, the researcher recorded and transcribed interviews with the participants’ consent. Because this research project was a doctoral dissertation that could potentially take several years to complete, the researcher took these added measures to ensure the data were retained in their full original form until such time that data analysis was complete.

Data analysis began with the first participant interview and continued throughout the entire interview process using Open Coding. Coding was carried out using a manual process in which the researcher printed the interview transcripts and went through line-by-line describing the content of each passage with a relevant code name. The use of a manual process was selected due to the researcher’s style of learning, which is a hands-on, tactile approach where data can be moved around and physically touched. Open coding resulted in thirty-two individual codes, and the core variable, or the participant’s main concern, was defined. In this study, “lack of resources

due to poor provider education and training in special needs populations” was defined as the core variable.

With the core variable defined, the process of selective coding began. Previously coded data were compared against one another and new codes were added, existing codes were renamed when appropriate, and codes were regrouped into common concepts or code families. The selective coding process resulted in seven core concepts. Lastly, theoretical codes were defined that integrated the seven core concepts into a hypothesis that explained how participants attempted to resolve their main concern. There were three theoretical codes defined. For a complete list of codes, please see Figure 1.

Results and Discussion

Participant Descriptions

The participants in this study spoke of their personal experience with childcare and preschool services for disabled children. Their children represented a range of childhood diagnoses including Autism, Down Syndrome, Sensory Integration Disorder, Attention Deficit/Hyperactivity Disorder, Communication Disorder, Social Delay, and Medically Fragile. The following is a brief description of each participant and her child's diagnosis.

Participant 1 (P1) is a married, stay-at-home-mom. She has a two-year-old son who was undergoing evaluation for Autism Spectrum Disorder, and she had been searching for childcare for approximately one year. Due to financial hardship, she and her husband had recently lost their home and were temporarily living with her parents.

Participant 2 (P2) is a married, stay-at-home-mom. She has a three-year-old daughter who diagnosed with Down Syndrome during routine prenatal testing, and she has been unemployed since her daughter was born. She has searched for childcare on a number of occasions so she could return to work, but has been unsuccessful locating a childcare that could meet her daughter's needs. She and her husband experienced financial hardship during her unemployment and as a result had to downsize their car, terminate their health insurance plans, and apply for State welfare assistance.

Participant 3 (P3) is a single mom. She has a three-year-old son who has Autism Spectrum Disorder, and she is employed in the childcare business. Her son currently attends a childcare program that is coupled with a two-hour early intervention program through the Birth to 3 Program.

Participant 4 (P4) is a married, working mother. She has a four-year-old son with Autism Spectrum Disorder who is 90% non-verbal, and she is employed part-time with a flexible job that

allows her to work from home if childcare is not available. Her son had been terminated from five childcare programs, and she had recently taken time off to spend with him and reevaluate her decision to continue working.

Participant 5 (P5) is a married, adoptive mom. She has a four-year-old daughter who is medically fragile, and a four-year-old son who was being evaluated for Autism. She is employed and her children attend an early intervention program where they receive developmental preschool services four days a week.

Participant 6 (P6) is a single, stay-at-home-mom. She has a four-year-old son who did not have a diagnosis at the time of interview, but was seeking evaluation for concerns with poor emotional regulation, slow speech, excessive crying, clinginess, and lack of boundaries. She works midnights at a low-paying job, and she lives with her mother. The participant receives State welfare assistance and her son is on State health insurance.

Participant 7 (P7) is a married, adoptive mom. She has a three-year-old daughter who is Medically Fragile with a cognitive delay that had not been fully diagnosed at the time of the interview. She was unemployed at the time of the interview, and her daughter was being evaluated by the local school district's Child Find Program to receive an IEP for developmental preschool services.

Participant 8 (P8) is a married, stay-at-home-mom. She has a four-year-old daughter who was diagnosed with Down Syndrome as a newborn. She has been unemployed since her daughter was one year old and began showing increasing signs of a delay. Since that time she has considered returning to work but has not been successful at locating a childcare program that could meet her daughter's needs. Her daughter received early intervention services through age three and started preschool with an IEP at age four.

Participant 9 (P9) is a single, stay-at-home-mom. She has a three-year-old son who was diagnosed with Sensory Integration Disorder and Attention Deficit/Hyperactivity Disorder. She has been unemployed for approximately eight months due to lack of childcare. She has experienced financial hardship due to unemployment and she and her children live with her sister.

Participant 10 (P10) is a married, stay-at-home-mom. She has a four-year-old son with expressive language delay, receptive language delay, and social delay; and a two-year-old son with expressive language delay and receptive language delay. She has been unemployed since the oldest child was eight-months-old due to lack of childcare. Her oldest child was evaluated by the local school district's Child Find Program and received an IEP for developmental preschool, which he attends half-days, four days a week. Her youngest child was evaluated by the Birth to 3 Program and the local school district's Child Find Program and received an IFSP for speech therapy through age three, at which time he will transition into developmental preschool with an IEP.

Core Concepts

The core concepts found in the data were the child, primary caregivers, daily life, getting involved, processes, early intervention services, and curiosity about the researcher. Based on the content of these codes, three theoretical codes were defined that integrated the concepts into a theory that explained how participants attempted to resolve their main concern. Those are: forced decisions versus choice; caregiver's struggle with early intervention services; and the caregiver's personal experience. Within each theoretical code, several factors were found to influence the participant's behavior. Point in which diagnosis was received, caregiver's support system, and socio-economic status were influencing factors related to the participant's sense of having made

forced decisions vs. having the ability to choose. Diagnosis and manifesting symptoms, repeat terminations, and the manner in which the child was treated were all influencing factors in the participant's experience with early intervention services. Contradictory emotions, self-blame, and lack of self-care, were all important elements of the caregiver's personal experience.

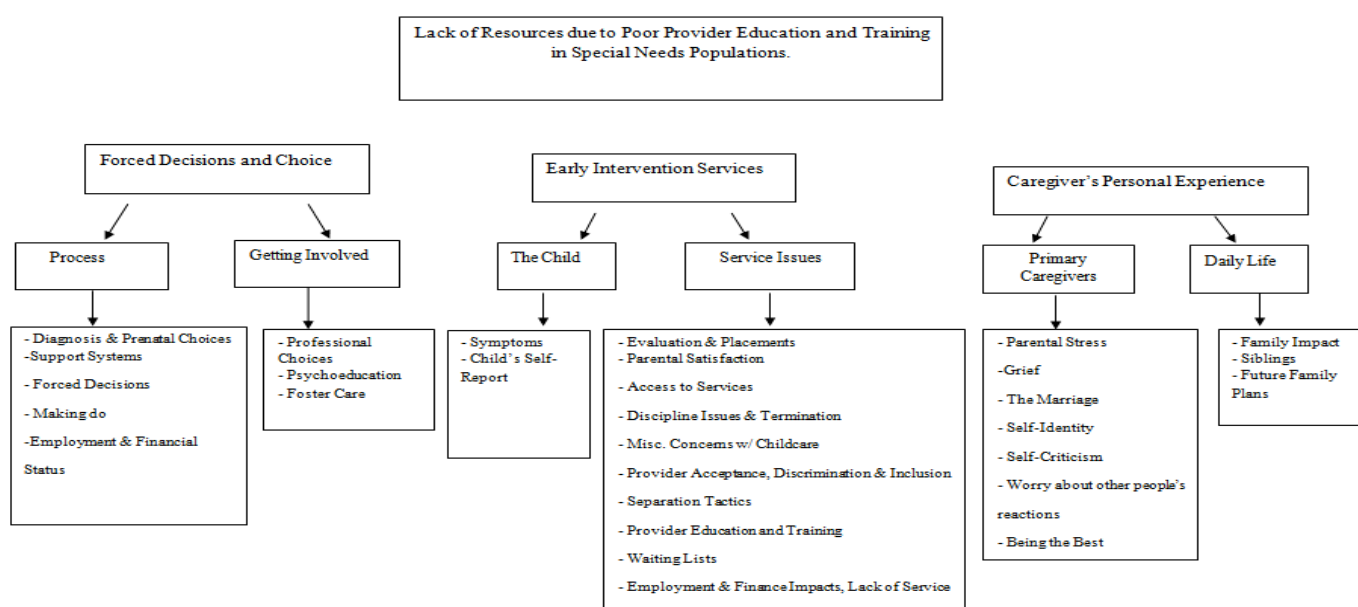


Figure 1. Hierarchy of codes.

Discussion

Ironically, in light of the fact that the researcher set out to examine the process by which caregivers make decisions regarding the early intervention services of childcare and/or preschool, central to all participants was a notion that a “process” did not exist when you are a parent to a child who has special needs. On the contrary, what was consistent across all families was a general notion that life is ever-changing, and when you parent a child with special needs, your entire process, childcare included, changes to incorporate the ever-changing, individual,

unique, demands of your child. The experience of having a disabled child is not *one* stressing incident, but an on-going life situation with continual new challenges that require parents to mobilize resources (Graungaard, Andersen, & Skov, 2011).

So, as you can see, there really aren't many families that have the opportunity to sit down and weigh out different options and make sound, informed decisions. These families are so desperate they take what they can get and they keep moving for fear if they stop they might sink. (P5)

Under "normal" circumstances I can see how finding childcare might be a nice set of steps and procedures that you follow. But when your child has special needs you're not so lucky. (P4)

If by process you mean the manner in which you literally feel like you are taking on the world to try and find answers that don't seem to exist, over and over again, then yeah, I guess there might be a process. I call it survival of the fittest myself. (P10)

In this study, the participants' sense of process, or lack thereof, was directly related to the core variable, which was previously defined as "lack of resources due to poor provider education and training in special needs populations." The core variable was found to relate to and influence all other main themes. Participants expressed unanimous concern with the limited mental health training required to obtain a childcare license, or to work in an early learning facility within Washington State. Directly related to provider education, was the concern with the manner in which childcare professionals presented themselves as fully competent to provide special needs childcare when, perhaps, they were not.

I do believe training in mental health would be helpful. When you take your child to see a medical doctor they don't freak out when the child starts bleeding or faints. Your ordinary person does. When I've taken my son to see the psychologist they didn't freak out when he had an episode, they knew how to react in the moment. These ordinary childcare providers don't know how to react and I can see they are overwhelmed. (P1)

I don't understand why someone with no training in special needs children is allowed to provide care for children with special needs. That makes no sense. There should be a required training before you can take these children into your childcare. (P2)

My biggest concern with childcare is the number of people that claim they have experience working with special needs children who actually don't have any experience. (P4)

Participants raise a valid point regarding the education and training requirements early learning providers must meet to obtain licensure as a Childcare Center or Family Home Daycare in Washington State. In their report “Early Learning Professional Development System Report and Recommendations,” The Washington State Professional Development Consortium (2010) set forth guidelines for the professional development and support of early learning providers. The report, which was governed by House Bill 1943 and passed during the 2009 legislative session, directed the recommendations to include a “Creation of a coherent system of professional development, including delineation of core competencies for early learning and school-age program staff, directors, and administrator,” and required “An analysis of gaps in available professional development programs and recommendations for programs to address the needs of early learning and school-age providers who serve children with physical or developmental disabilities, behavioral challenges, and other special needs” (p. 2).

The Washington State Professional Development Consortium cited “moderate to low levels of education” in the early learning work force as a challenge to building a statewide professional development system, and argued that “low-wage early learning professionals cannot afford college on their own and will not be able to achieve higher degrees and credentials without substantial public investment ” (p. 4).

Among its many findings, The Washington State Professional Development Consortium (2010) found that:

- Approximately 25 % of early learning professionals in Washington have obtained a two or four-year degree in any subject. (p. 4)
- 59 % of center-based providers have some college or a degree while 40 % have a high school diploma or less. (p. 23)
- 57 % of family care providers [daycares within a provider’s home] have some college credit or a degree while 37 % have a high school diploma or less. (p. 23)
- Of the family childcare providers surveyed, 15.5 % reported having an associate degree in Child Development or a CDA; only 4% had a bachelor or graduate degree in Early Childhood Development. (p. 4)

Washington Administrative Code (WAC) 170-295 “Minimum licensing requirements for child care centers” and WAC 190-296A “Licensed family home child care standards” outlines the minimum qualifications childcare providers must meet to work in licensed early learning facilities. Those qualifications are outlined below:

Table 1

Minimum Education Requirements-Child Care Centers

Title	Minimum total college quarter credits in early childhood education	Of the total credits required, the number that must be college quarter credits	Of the total credits required, the number of department approved clock hours	Notes
Director, child care centers	10	7	3	
Lead teacher, child care center	0	0	0	High school education or equivalent
Assistant, child care center	0	0	0	No education requirement
Volunteer, child care center	0	0	0	No education requirement

Table 2

Minimum Education Requirements-Family Home Child Care

Title	Minimum total college quarter credits in early childhood education	Of the total credits required, the number that must be college quarter credits	Of the total credits required, the number of department approved clock hours	Notes
Licensee, family home daycare	0	0	0	High school education or equivalent
Primary staff person, family home daycare	0	0	0	No education requirement
Assistant/Volunteer, family home daycare	0	0	0	No education requirement

For certain employees (i.e., directors, program supervisors, lead teachers, etc.) in child care centers and family home child care providers, Washington State requires an initial 20 hours of training, known as “20 Hours Basic STARS,” in addition to varying requirements of continuing education on a yearly basis. This initial training provides a general overview of operating a childcare business and includes such things as basic hygiene, safety, food preparation, and tax records. The topics for ongoing yearly training are selected by the participant and can cover any range of childcare topics. Combined, none of the minimum education requirements specifically address special needs populations and disabilities.

It is important to note that, in Washington State, not all preschools are operated under the Department of Early Learning (DEL), and, in fact, most are not. The Early Childhood Education and Assistance Program (ECAP) and Head Start are both statewide programs that offer early intervention preschool under the Department of Early Learning, and enrollment is limited to families who meet certain income and disability requirements. Preschools may also be owned/operated by religious institutions or co-op parent groups, neither of which are required to be licensed; they may be certified by the Washington State Office of Superintendent of Public Instruction; or they may be operated by licensed childcare providers who offer a structured half-

day preschool program as part of their child care services. As such, the educational requirements vary widely depending upon the type of preschool.

The valid concern that parents have over lack of competent resources due to provider education and training with special needs populations leaves the door open for many important questions. How do parents attempt to resolve their concerns? What factors influence their behaviors? How do they navigate the distinct early learning needs of their disabled child against the odds? This research found three major themes, or theoretical codes, that combined to create a theory of how parents tackle this issue. First, the research demonstrated that parents who learned of their child's disability in a prenatal diagnosis or prior to an adoption identified with having a greater sense of choice and control over their circumstances, and their ability to make competent, informed decisions regarding their child's needs. The same was true for parents who had a primary support system in a spouse or significant other, thereby offering additional options over those realized by a single parent. Second, due to poor provider training and education with special needs populations, caregivers are more likely to keep their child in the home and work around whatever financial hardship might result. And lastly, for all participants in this study, caring for their disabled child was difficult, yet rewarding, and it is the unconditional love that these caregivers have for their children that drives them to give tirelessly against the odds.

Forced Decisions and Choice

In discussing the overall process of having a child with special needs, and how one goes about making decisions regarding early intervention programs, such as childcare and preschool, primary caregivers were divided into two camps: those who felt that they have a choice in the overall process, and those who felt that decisions were somewhat forced upon them for any number of reasons. This is not to say that parents in the first group always had their preferred

choice, especially with regard to the early intervention services their child would ultimately utilize; however, these parents seemed to approach the disability from a state of being informed, and they displayed a general sense of confidence in their ability to make the best decisions for their child, including the difficult decisions of appropriate childcare and preschools to address their child's distinct learning needs.

Factors that contributed to the primary caregiver feeling as though they had a choice in the overall process included the point in time when the diagnosis was made, the caregiver's support system, and the family's socio-economic status. For example, caregivers who learned of their child's diagnosis during pregnancy, or prior to adoption, identified with the ability to make informed decisions, knowingly accepting life with a disabled child, and acknowledging the fact that their lives would be significantly different from the life they had planned.

We learned she has Downs while I was pregnant and we made the decision that it didn't matter, she was our daughter regardless of what disability she had. The doctor advised that I have extra test to confirm the severity so I could make an informed decision. I refused the tests and told him I was making an informed decision as a mother. Knowing this child's life and future depended on me was all the information I needed to know. (P2)

I started foster care specifically for a child who was severely medical fragile. She was disabled, could not get out of bed, could not speak, had a feeding tube, she was severe...I mean can you imagine, here this child can't move, can't speak, can't eat. What would happen to her out there? So, I did it. I got my license and that's the first child I took into my home and I have since adopted her. (P5)

My daughter is adopted and we knew she had special needs when we adopted her. We knew her mother had no prenatal care whatsoever and she was born with two holes in her heart that required immediate surgery. We knew the surgery was a success for her heart, but there were sure to be residual effects and unknown complications or disabilities. We had a choice and we chose her. (P7)

Initial experiences with healthcare professionals have been shown to have major, lasting influences on the parent's ability to cope with their child's condition (Graungaard & Skov, 2006), and early identification of a disability has been associated with a reduction in family

stress level by giving the family specific ideas for intervention strategies and a diagnosis which facilitates the family's ability to access medical and other supports for their child (Charman & Baron-Cohen 2006, as cited in Branson et al., 2008, p. 525). Parents who received a prenatal diagnosis, or a diagnosis prior to adoption, identified with having a choice and they readily invested themselves in appropriate training and education and began preparing for life with a disabled child months before their child arrived.

The day the doctor told me I felt like the air had been knocked out of me at first but the feeling didn't last long at all. I am a doer by nature and I wasn't about to sit back and let the most important thing in my life go undone. I made it my job from that point forward to learn everything I could about Downs, to get involved in the Downs community, and to educate myself to the best of my ability so I could offer my child the type of upbringing that she deserved. (P2)

It was like a crash course in medical school. It was hell. I knew nothing about disabilities at that point in time, and really nothing about the body as far as anything abnormal was concerned. I had always been healthy, my spouse was healthy, I had no reason to know about disabilities. Then all of a sudden I had the most important reason of all and I needed to know all I could know within the next five months or so because she was going to be born and there was nothing I could do to slow down that process. (P2)

I knew what the doctors told me prior to the adoption and I knew I had to prepare to give this child, my child, everything she needed to grow and be healthy. Yes, it was scary and a bit overwhelming but I dug in and took it upon myself to read every piece of relevant literature I could, to consult with physician after physician, to join support groups, you name it. I didn't wait for anyone and I didn't have anyone waiting for me. (P7)

Also contributing to the notion of choice was the primary caregiver's support system. In a study on family and work predictors of parenting role stress in two-earner families of children with disability, Warfield (2005) looked at 51 married couples whose children were aged two and under at the time of their referral into an early intervention program, and who met one of the following three criteria: (1) diagnosis of Down Syndrome confirmed through medical record review; (2) motor impairments with demonstrated evidence of abnormal muscle tone or coordination deficit along with delayed or deviant motor development with or without other

areas of delay; or (3) demonstrated evidence of delays in two or more areas of development, with no established diagnosis or cause that implied a specific prognosis.

Measures included parent well-being, couples characteristics, and work characteristics. Parent well-being was measured by the Parent Domain of the Parenting Stress Index (PSI). Both mother and father completed the PSI on separate forms. Couples characteristics was comprised of resources and the challenges faced by couples. Resources included income, which was defined as an ordinal level variable with three categories, and spousal support which was rated on a scale of (0) not at all helpful to (4) extremely helpful. Parenting challenges included several variables such as number of children in the household, childcare, and the characteristics of the child (i.e., type of disability, behavior problems, and cognitive abilities). Work characteristics included work rewards, as measured by participants rating their job on a scale from 1 to 7 to indicate boring versus interesting; and work demand, as measured by the number of hours worked per week.

Using a multi-level modeling approach of statistical analysis, Warfield (2005) found the following:

- Greater spouse support was related to lower maternal and paternal stress
- Having more children predicted greater maternal and paternal parenting role stress.
- Mothers who reported high work interest and had children with fewer behavior problems reported lower stress than mothers who were also parenting a child with few behavior problems, but who had a low work interest.
- Increased difficulty in finding reliable childcare for their disabled child was a predictor of greater parenting role stress for fathers but not mothers, perhaps because fathers may be called upon for childcare if another provider is not available.

Spousal support has also been shown to play a critical role for parents following diagnosis (Bruns & Foerster, 2011), and extended support through family members and community has been found to be a significant coping resource that reduces stress and helps to create feelings of cohesion, emotional support, self-efficacy, and acceptance of the disabled child (Graungaard et al., 2011).

Primary caregivers with a supportive spouse or significant other expressed a heavy reliance upon their partner and acknowledged the dedication, sacrifices, and teamwork that it takes to raise a child with special needs. Having a partner to share the load was not only emotionally invaluable, but it also offered parents additional options when it came to important decisions, such as financial planning, medical insurance, and everyday care of their disabled child. Whether pulling together a combined income to pay for additional services, relying upon one another to alternate time off from work to cover child care, downsizing to a single income and making sacrifices as a couple, or having the luxury to be financially stable with a single income, thereby freeing one parent to stay at home with the child, primary caregivers with a spouse or significant other realized additional choices over that of a single caregiver.

We did everything together. There were nights we would just cry for hours and grieve that loss of the dream we had for our child but we found a lot of strength in each other and we would wipe the tears, pull together, and attend the next parenting class...It's nice to look back on. When you're in the trenches, so to speak, you don't always see the good or realize how much you are depending on someone. When I look back it gives me a lot of comfort to see that support coming from my spouse and that I was able to support him...Financially we were blessed that we were not dependent upon my income. We had good health insurance with my husband and there were little things we could cut back on that would allow me to stop working. I don't even remember if I had to approach my husband and tell him I wanted to stop working or if it was just an obvious mutual decision. He fully supported me staying home and it just seemed like the right thing to do at that time. We were both happy our daughter was with mommy all day. (P8)

Before I was working and I at least made enough money to pay our car payment, utilities, and buy groceries. My husband's salary paid the rent. Now, his salary is the same and still pays the rent but we had to downsize on our car, cut back to the minimum on

utilities, and we receive cash assistance for food. I'm not complaining; in many ways we were blessed to have each other and even have the option for me to quit working. Not everybody has this...We are in this together, and without each other I don't think we would survive. We support each other, for better or worse, so that we can support our daughter to the best of our combined ability. (P2)

Unlike primary caregivers who learned of their child's disability during pregnancy or prior to adoption, primary caregivers whose child was diagnosed in the days, months, or first few years of life, expressed feeling forced in their decision-making capabilities. For these parents, there was the added difficulty of an unexpected diagnosis that changed their family plan and what they had envisioned for raising their child.

We had all the typical excitement and business that goes with just having a baby, but within a few hours of birth when things settled down I looked at her and I remember asking my husband do you think something is wrong with her?...When the doctor came in he told us he had ordered tests and before we knew it there were genetic counselors and a whole host of people coming into our room to talk to us about Downs. I'm not sure we have ever felt like we were in control from that point forward. (P8)

At about 9 months he stopped cuddling so to speak. He used to let me hold him and feed him and he loved to be in the rocking chair with me snuggling. Not anymore. Our world abruptly changed at 9 months. (P1)

I knew by six months of age that something was different with our son. Although he walked by six months of age, was very healthy, and appeared to be meeting all the major milestones, I just knew something was different. From that point on I realized things would not be as I had perfectly planned them to be. I wasn't sure exactly how they would differ, but I knew I did not have the unlimited opportunities that I had planned. (P10)

I started to see a change when my son was about 18 months of age. He had been such a vibrant little boy up until that time, and of course I was like a lot of moms and had dreams and aspirations of making him the next all-star so to speak, but then things started to change and it was like night and day. That was when Autism entered our life and things have never been the same. Your child is changing, you are changing as a parent, and your plans and daily mode of operating are changing. I wouldn't say you lose your dreams for your child, but you learn to adjust and evolve those dreams into what the child is capable of doing/becoming. (P3)

For single primary caregivers without a spouse or significant other, there was little mention of having someone to share the emotional burden. Important decisions, such as financial planning, medical insurance, and everyday care of their disabled child were carried out based upon what was available, not necessarily upon what the primary caregiver would have otherwise chosen. In some cases, parents had no choice but to remain unemployed with their only source of income being welfare benefits, such as WIC and Temporary Assistance for Needy Families (TANF).

I live with my mom. She watches my son at night so I can work midnights at a crap job making minimum wage. I can't leave him in daycare to work days and my mom also works days so my only choice is to work nights. (P6)

I would take anything at this point because I need to work. I would be willing to take just about any type of work that fit with the childcare schedule...I haven't been employed since he was born. I have no choice, I have to take care of him, there is nobody else. (P1)

It is important to note that every single primary caregiver in this study expressed nothing but complete and unconditional love for his or her child. For those parents who felt like they did not have much of a choice and that decisions were somewhat forced upon them, there was never any inclination they would change their decision to become parents, or to parent that particular child, if given the option. These parents loved their children nonetheless, and they were determined to provide for the health, safety, and welfare of their child in any way possible.

Struggle With Early Intervention Services

Early intervention services play a pivotal role in the future success of infants and toddlers identified as having a cognitive or developmental delay. For example, research data has shown that children who attend high quality programs gain intellectual, social, and emotional competence, do better academically, and lead more productive adult lives (The Washington State Professional Development Consortium, 2010). As a parent, we ultimately want our child's time

away from us in daycare or preschool to be full of exciting adventures, socially stimulating, and most of all comprised of nurturing, positive interactions between child and provider. We entrust child care providers with the most precious assets we have on earth, and we want to know our children are well taken care of throughout the day. For a child with special needs, there is an important balance between finding a program that can accommodate the child's disability by making adjustments to meet their distinct needs, and at the same time offer an inclusive learning environment that allows the child to flourish, not to be singled out, and to experience a range of developmental stages among their peers.

Overall, most of the participants in this study (80%) did not have positive experiences with the early intervention services of childcare and preschool, and most were disheartened by their search to find suitable care. The main factors that contributed to the participant's experience included the child's diagnosis and manifesting symptoms, repeat terminations, and the manner in which their child was treated. The caregiver's experience with early intervention services is the most closely related theoretical code to the main concern among all participants, that is, lack of resources due to poor provider education and training in special needs populations. It is within the caregiver's experience with early intervention services that we gain a clear understanding of what can occur when a provider lacks competent training, and just how difficult such situations can be for families seeking services.

Of the primary caregivers included in this study, 50% (N = 5) were stay-at-home-moms at the time of interview. Three participants were actively seeking a suitable childcare or preschool program but had been unsuccessful in their search. The remaining two participants expressed a desire to find childcare earlier in their child's life but, due to their search experience, had since resolved to remain stay-at-home-moms. Of the 50% of caregivers who found a suitable

childcare or preschool placement, three children were enrolled in licensed childcare centers, two of whom had previously been enrolled in a minimum of five different, unsuccessful, placements prior to their current enrollment. Two children attended pre-kindergarten or other early intervention services half a day, and are home with their mother the remaining half, due to the fact that a suitable half-day childcare program that could provide care following their morning programs is not available.

Depending upon the diagnosis, manifesting symptoms ranged from slightly disruptive behaviors, such as talking over people and refusing to join seated activities, to severe head banging, social withdrawal, impaired communication, bullying, name calling, and frequent loss of control exhibited by severe outbursts of kicking, screaming, and crying. Children with a co-morbid medically fragile diagnosis had severe physical limitations, including inability to speak, eat, or move without assistance.

Ongoing parental satisfaction was particularly low among all parents who had utilized childcare or preschool services for their disabled child. First, it took parents of a disabled child a greater amount of time to find a qualified provider than it did parents of typically developing children. For example, in a study by Bitterman, Daley, Misra, Carlson and Markowitz (2008), the researchers found

- Once parents began looking for services, it took an average of 76.9 days for parents of children with ASD to find services for their children and an average of 83.8 days for parents of children with other disabilities .
- 22% of parents of children with ASD (compared to 12% of parents of other disabilities) reported that it took a lot of effort to locate preschool special education services for their child. (p.1513)

Second, participants expressed a heightened level of anxiety and fear over their child's enrollment status.

You respond to daycare ads, you call, you explain your situation, they enroll your child for a few weeks, and then you show up one day and your child's enrollment has been terminated. Sometimes you get a week's notice, other times it's immediately. You go home and you do the same thing all over again. It gets to the point that you actually get anxious when you go to pick your child up because you fear they have been terminated. My son is on his fourth daycare. It seems like just about the time I start thinking this one is going to work, and I try to find a job that works with the location and hours of the daycare, he gets terminated again. The stress of switching to one daycare after another is enough to drive a parent down. (P4)

My son is on his fourth daycare. It seems like just about the time I start thinking this one is going to work, and I try to find a job that works with the location and hours of the daycare, he gets terminated again. The stress of switching to one daycare after another is enough to drive a parent down. (P9)

The issue of unstable enrollments reaches beyond the immediate situation wherein a parent has just learned their child's enrollment has been terminated and the parent may be feeling angry, embarrassed, or sad. Financial difficulties and risks to employment security may also occur when a child has an unstable enrollment status within childcare settings. According to most parent handbooks that outline the rules and policies of childcare service providers, providers generally reserve the right to immediately terminate a child from the program if the child engages in repeat behaviors that are disruptive and incompatible with the learning environment. With such terminations, parents are generally not refunded their deposit or other prepaid fees, so not only are parents faced with the reality that come tomorrow morning little Johnny no longer has daycare, but they will also have the increased financial burden of placing another deposit at the next daycare placement. For parents who are on their third, fourth, and even fifth daycare placement, daycare deposits can quickly become a financial burden.

Parents who miss work due to lack of childcare generally forfeit hourly wages if they are not a salaried employee or have personal time benefits. A parent's job may be terminated, or their future standing for employment promotions may be hindered if the additional time off infringes upon the parent's ability to perform work duties as assigned and on schedule.

Parents have to leave work, which they don't mind in terms of taking care of their child, but it puts the parent's job at risk if he/she is constantly having to miss work because they don't have a provider. They generally just quit and stay home with the child. (P5)

The impact on employment is particularly important now when the work force is witnessing an increase in working mothers, who traditionally have held the role of primary caregiver to young children not yet enrolled in school. While more and more mothers are deciding to enter the work force and provide for their families, there is still a higher rate of women in the labor force who have children over the age of six than those with children younger (70.6 % and 63.9 % respectively) (Bureau of Labor Statistics, 2012). The disparity in working mothers with older and younger children could, perhaps, be an indicator of the challenges associated with being a working mother during the early years of a child's life. On the other hand, as children get older and spend the greater majority of their day at school, mothers have more time for themselves and greater flexibility to return to the work force. For women with children who have special needs, finding balance between work and family is all the more difficult, and many women simply find themselves unable to keep up the demands of both. As a result, women frequently make the decision to become stay-at-home-moms, thereby reducing their family's income, or they accept employment offers that may be less demanding or less desirable and under-utilize their skills and training (Warfield, 2005). Either decision often results in financial burdens to the family, and parents can find themselves in the position of having their homes foreclosed, down-sizing to apartments, having automobiles repossessed or sold, and defaulting on debts that are then sent to collection.

There have been drastic changes. We moved to a much cheaper, lower quality apartment for starters. It's not in as good an area and I worry about that as a mom. We also have one vehicle and could have to resort to selling that and taking the bus. We never go out or do anything that costs extra money. We do go to the park a lot and that's nice because it's free and we go as a family. It's about our daughter now and as long as we can clothe,

feed, and provider for her shelter then we are quite content spending every day at the park if it makes her smile. (P2)

Well I don't mind telling you that we lost our home recently. It's not entirely based on having a child with special needs, the economy is definitely a factor. My husband's job down-sized and he had to take a less-paying position in order to keep the job. His position was closed and since I can't really work because we don't have childcare then I can't help pick up the slack. We just couldn't make ends meet anymore and we got behind on the mortgage. Now we live with my parents who are elderly. (P1)

Also related to the primary caregiver's experience with early intervention services, was the issue of inclusion and the level of provider acceptance towards the disabled child.

You know when they are little they are cute, everyone looks at the baby with Down Syndrome and says oh they are so cute, you want to play with them. When they start getting older and the reality sets in, people's attitudes change...when they are small they are supposed to be in diapers, they aren't supported to know how to talk, they are supposed to be dependent upon you, it's not a big deal to pick them up and carry them around. It's when they start getting older they should be out of diapers, they should be talking, they are heavy to carry around. It's when they don't do what they are expected to do that people become frustrated. (P5)

He's not the most fluent toddler when it comes to language but he would tell me he played alone or teacher had him play a game by himself or with her...I'm not always sure it's best to have him play with the other children because he can get a little out of hand but it seems there should be a balance of social play and then play that is designed to help him achieve things on his own. You know play that would focus on improving his skills. I don't see that balance, I see him isolated by himself or directly with a teacher at all times. (P6)

They acted like she was a freak, as if they were afraid of her. I mean they would totally ignore her and her behaviors and just let her do whatever because they were afraid to interact with her. I mean she wears really thick glasses, and yes she looks a little different but these were adults treating her this way, not children. They did nothing to challenge her or help her succeed, they basically maintained her. I would go in and every kid would be eating and she would be off playing alone. (P7)

This participant's concerns highlight possible examples of discrimination and lack of inclusion, both of which are protected rights under Section 504 of the Rehabilitation Act of 1973

and IDEA of 1990. While it seems there is an overall general consensus that integrated childcare settings are beneficial to both children with disabilities and their typical developing peers, what is not in overall agreement is the meaning of an integrated setting or the manner in which such a program should be facilitated for all children. For example, in a study by Lieber et al. (1998) teacher's beliefs about inclusion and the manner in which those beliefs were enacted were examined. The results indicated that while teachers overwhelmingly believed integrated settings were beneficial for all children, there were multiple variations in the way teachers interpreted and enacted their beliefs. For example, although teachers in some programs believed "all children are equal parts of the whole" (p. 93), these same programs failed to adapt lessons for children with disabilities and "there was recognition that performance expectations should be different" (p. 94). In another program, teachers believed that all children were members of the group, yet researchers observed a "narrow band of acceptable behavior [and] a higher premium was placed on conforming to group norms that were set by the teacher's expectations" (p. 95).

The delicate balance between providing for the distinct learning needs of a disabled child, while at the same time offering maximum inclusion so the child is not singled out and treated differently, is a difficult one for anyone to obtain and provide. And, while parents acknowledged the struggle that providers are up against in trying to create an inclusive early learning environment, they also felt that advanced training and education with special needs populations would ultimately enhance the provider's capabilities to offer such and would be seen as a benefit for all involved.

Caregiver's Personal Experience

When a child has a disability, the emotional burden on a caregiver can be tremendous. The day-to-day demands of caring for a child with severe behavioral symptoms, or medically

fragile needs, are exhausting in and of themselves. Additional stressors, such as lack of childcare, limited finances, and job stress can easily exacerbate the already heightened levels of stress, anxiety, and fatigue experienced by many parents of disabled children. Left unchecked, the burdens of caring for a disabled child can have significant impact on the caregiver, the marriage, and the family, including other siblings. Restricting visitors to the home, reducing family outings, and breakdowns of community involvement are ways in which the child's behaviors have been found to directly impact the family (Brown, Geider, Primrose, & Jokinen, 2011).

Participants demonstrated many difficult emotions including anger, sadness, guilt, grief, and fear. They spoke of high levels of anxiety, depression, stress, and fatigue, and they demonstrated self-blame difficulties with such things as lack of self-care.

It's a dream of what you think your child will grow up to be, to do, and when a child has special needs that dream is often lost. Most parents don't want to admit that out of guilt, I mean nobody wants to admit they aren't happy with what they got. It goes against the very nature of being a parent. (P5)

Sure I get mad, or I get the flu, or any number of things can happen that make me want to hibernate somewhere and not show my face until spring. Sometimes I get really down and I beat myself up about how I reacted. (P2)

I am exhausted, there are simply no better words to describe how I feel. I am mentally and physically exhausted. On any given day I feel angry, then sad, then tired, it's a cycle that doesn't stop. Don't get me wrong, he's my son and I love him with all my heart, but I get angry and question why him? Why did he have to be born with this? It's so hard. (P9)

I am very lucky to have found a childcare placement that can meet my child's needs while I am at work. For that, I can't complain. That doesn't mean I can't, or don't, complain about the situation in general. I battle anger and frustration all the time. Why did Autism have to choose my son, he was such an outgoing, vibrant child. I will exhaust myself to the end to get him the services he needs as he grows up, but hell yeah I'm angry that I have to do that! I'm sad at the lost opportunities. I wanted so much more for him and I know this isn't about me, but it's heartbreaking, depressing, and anger provoking when your child is ill and you can't make it go away. (P3)

At the same time, participants expressed nothing short of unconditional love for their child and complete gratitude for the blessing the child has been in their life.

It's very easy to get worn out when your child has special needs but even so, I don't think most parents would change the situation if they could. This is your child and all their quirks and their disability is what makes them who they are. They wouldn't be the same without the disability and as a parent my life would not be the same. My child is my biggest blessing, she's my heart. (P2)

Despite her delays and known health conditions, every element of my being knew this was my child, I was meant to adopt her. Some people might ask why adopt a child so sick? The answer is simple, this is my child. I love her for who she is and I would do it all over again without hesitation. (P7)

I cannot imagine life without my little guy. He is who he is, and I wouldn't change him for nothing in this world. His delay is part of what makes him, him. GOD knew exactly what I needed when he gave me this child and not a day goes by that I don't say a prayer to thank him. (P10)

Despite the fact that almost all participants spoke of being fatigued, needing more private personal time, or needing quality time with their spouse or significant other, none of the participants had a routine that included a regular element of self-care. Self-criticism was a reoccurring component of the participant's stories. At times, participants took responsibility for circumstances that were not necessarily within their control (i.e., available childcare resources), or they were critical of themselves about past choices that may, or may not, be contributing to their current circumstance.

I get very upset with the whole childcare situation, or the fact that there is no good solution. I start to feel even more depressed and worried than I was before. I blame myself for some of the things that I go through with the whole childcare experience...I don't know, maybe if I spent more time trying to find the perfect provider. Or maybe if I could just stay at home and full time. It's my responsibility to make sure he's taken care of and if I'm leaving him with the wrong people then it's my fault. (P4)

I have always lived with my mom. I got pregnant just out of high school and never got off to a good start I guess you could say. I'm probably not smart enough to get into college anyway... I've made some stupid choices, ran with the wrong crowd, got mixed up with the wrong guy, now look at where I'm at. (P6)

There are times that we look back and question if we should have done more. Given the slightly abnormal routine prenatal tests, I could have been more proactive with follow up testing. I don't know if knowing would have made a difference, but some days when you

feel like it's you against the world you question those things. Could I be doing more now? Should I have done more back then? I feel like the weight of the world is on my shoulders and I have to come through for this child. If only I could do this better, or do that better. I have an uncanny ability to criticize myself and not even know I am doing it until days later when I feel like I have a black eye and realize it's all the negative self-talk. (P8)

I went through a phase where I was too hard on myself. I exhausted all efforts to find a suitable childcare program and I knew I had exhausted all efforts. I had given it my best. Even so, I would still lay in bed at night and ask myself what is wrong with you, why can't you find a childcare you are happy with? You must be missing something, not talking to the right people, you have to try harder. (P10)

Contradictory emotions, self-blame, and lack of self-care are part of the makeup of parenting a disabled child. The caregiver's personal experience is difficult to fully grasp and it's a topic that participants were hesitant to discuss, as they have become accustomed to placing their needs second to the needs of their child. That being said, it is a topic far deserving of further research and acknowledgment.

The Grounded Theory

The topic of childcare for children with special needs is/should be an all-encompassing discussion that not only examines the distinct needs of the child, but also the macro system which affects the types of resources available to families; the mesosystems in which these families operate; and the factors of the immediate microsystem that are faced with the difficult day-to-day decisions. One might argue that in a perfect world, children who have special needs would be born to wealthy, two-parent, families where one or more caregiver can either choose to stay home and care for the child, or the family can afford to privately hire a childcare provider with education and training in special needs populations. In the alternative, as this study demonstrates, we must consider that the perfect world does not exist and there are families struggling with the issue of inadequate childcare on a daily basis. What this study demonstrates is a number of psychosocial factors that, if present, help aid the family in confident decision making, help to mitigate the impact to the family's emotional and financial well-being, and ultimately

shape how the participants attempt to resolve their core concern, that is lack of resources due to poor provider training and education in special needs populations (Figure 2 provides a visual representation of the factors that encircle the primary caregivers in this study.) These factors include the point in which caregivers find out their child has a special need (i.e., prenatal, prior to adoption, after the child is born); the primary caregiver's support system, specifically whether they have a spouse or parent who is involved in the day-to-day care and decision making for the child; and the financial stability of the household. In making decisions regarding the best option for their child's day to day care, caregivers who learn of their child's disability in a prenatal diagnosis or prior to an adoption realize a greater sense of choice and control over their circumstances. This is also true of caregivers with a primary support system such as a spouse or significant other who contributes to the financial status of the household. Both groups identified with having increased confidence in their ability to make competent, informed decisions regarding their child's needs. On the contrary, families who learned of their child's diagnosis later in life and were faced with unexpected changes, as well as those parents who did not have a strong support system and were solely responsible for the financial status of the household, identified with having decisions forced upon them and having less control over their individual situations. These caregivers discussed greater financial burdens, increased caregiver stress and a strong sense of isolation from the outside world. Regardless of which group the caregiver belonged to, two things were unanimous: First, is a belief that lack of training and education in special needs populations has resulted in a substantial lack of childcare resources from which the family can choose. Second, due to lack of resources in special needs populations, caregivers are more likely to keep their child in the home and work around whatever financial hardship and overall microsystem impact may result.



Figure 2. Visual representation of theory.

Limitations and Implications

Limitations of the Study

One of the major limitations of this study was the lack of demographics known for each participant. There were no demographic inclusion criteria for participation in the study, so as not to discourage interested caregivers from participating. Furthermore, if the participant did not speak of demographics, the researcher did not inquire. This decision was made in an effort to stay with the notion that in grounded theory the researcher does not lead or force the data, but rather relies upon the participant to tell the researcher what is important. As such, there is not information as to the identified race, culture, or age of the participants so we cannot determine how these factors influence the participant's experience as a primary caregiver of a child with special needs.

Originally, there were a few potential male caregivers who had expressed an interest in participating; however, despite multiple attempts to accommodate their scheduling, they later retracted their interest due to hectic work schedules. Due to the fact that all participants in this study were female primary caregivers, future studies on male primary caregivers would likely lend a somewhat different perspective.

Another limitation of this study was that it did not include the perspective of the providers. Given that a large portion of the findings were based on circumstances directly related to the providers, such as provider training and education, or caregiver satisfaction with programs and services, the provider's perspective might have added clarity to issues raised by the participants. Future studies on this topic might consider looking at the experience of the primary caregiver as well as that of the service provider, and examining how the individual experience ultimately contributed to the shared experience.

There were limitations to this study that were imposed by the inclusion criteria. First, the study is restricted to Washington State as the researcher was particularly interested in local childcare and preschool services for disabled children. As such, the findings were influenced by Washington State laws that govern the licensing standards for childcare providers, as well as Washington State disability laws to which early intervention service programs must adhere. Because such laws vary by state, the outcomes might be different if the participants experience had been based in another demographic region. Second, the upper age range for the children in this study was limited to four years of age, because the researcher focused the study on children who were not yet enrolled in school full-time and therefore likely to need childcare/preschool on some level. Several participants and professionals with whom I spoke suggested that childcare services for older disabled children are of great concern. By limiting the age of the children in this study, I missed the opportunity to explore this process from the prospective of a parent with an older disabled child.

Implications

This research is significant because it addresses a very important, and highly overlooked, topic in the areas of special-needs children and early education: the process that primary caregivers go through when selecting a childcare placement for their special-needs child. While Federal and State laws such as Section 504 of the Rehabilitation Act of 1973 and IDEA may have placed a higher emphasis on special-needs children once they are enrolled in a childcare placement, it is important to note that post-enrollment success is but one part of the complex, multifaceted puzzle. To date, there is little consideration given to the primary caregivers and the essential task they have in selecting a childcare program that adequately meets the distinct needs of their disabled child.

Based upon the themes that emerged from the primary caregiver's interviews, this research lends important information for psychologists, teachers, social workers, and the Department of Early Learning regarding the challenges that caregivers face as they make decisions regarding their child's placement in a childcare or preschool setting. This study revealed a number of concerns with provider education and training in our state, it highlights the need for advocacy around additional required mental health training among childcare providers, and it highlights, what I would argue is, a systematic discrimination and injustice to children who have special needs and their parents. Despite the detailed requirements for owning/operating a childcare program in Washington State, there are no specific requirements that providers have mental health training prior to providing childcare to children with special needs. As a result, there are no built-in protections that would facilitate a safe, appropriate childcare service for this population. This begs the question, why not? Why aren't these children entitled to a childcare program where their provider has state-mandated, appropriate education and training to provide special needs services?

This study provided an inside view of the role that early diagnosis, spousal support, and financial status plays in a caregiver's experience of experiencing forced decisions versus choice, and it highlighted the multifaceted, complex, personal experience of the primary caregiver and their families. As psychologists who work with children and families, it is critical that we understand the challenges that families face in this situation. Sensitivity to such challenges should be present when working with families and psychologists should consider wrap-around service models that place the family in contact with various family resources within the community (i.e., referrals for local Birth to 3 programs; Washington State Child Care Resource and Referral Network to assist parents in locating a childcare provider based on a number of

search criteria; and appropriate local support groups that are focused on particular childhood disorders). By working within a community model, psychologists can help empower the family by placing them in contact with appropriate resources, support, and psychoeducation that is coupled with individual and/or family therapy and they can advocate for improved education for childcare providers.

Role of the Researcher

I am a mother to three boys, ages five, three and two years, and I have a twelve-year-old stepson. I became interested in the topic of childcare for children with special-needs six years ago, during the time that I was pregnant with my oldest son. At that time I was working full-time in a demanding corporate job, my husband and I had recently purchased our new home, and we were unsure if we could make ends meet if I stopped working and became a stay-at-home-mom. As we considered our options, one thing was clear: if I were to keep working, we would need to find a childcare placement for our son once he reached three months of age.

After months of searching for what I considered a “qualified” childcare placement for infants, I had no promising leads, and I had literally exhausted myself in the process. Desperate to find a childcare placement, I began talking to every mom I could contact in my local community to learn more about their experience with childcare in the area. It was during this time I came into contact with several mothers whose children had been diagnosed with a special need. As I listened to their stories, I realized how amplified their experience with childcare had been compared to mine. I had been blessed to have a healthy son with no special needs (or none that I knew of at that time), and I found the whole subject of childcare exhausting and stressful. As a mother I could not begin to fathom what it must be like to have a child with special needs and negotiate the childcare search process. As days turned into weeks and I heard story after story of childcare experiences for special-needs children, I realized this is an area where psychologists could potentially make a great impact through community leadership and mental health expertise.

Ultimately, my husband and I decided I would stay home with our son because I could not find an acceptable childcare placement. I call it a mother’s intuition, but something in me

knew my son was not ready for full-time childcare. Within the year of this decision, my son started to display behaviors that were indicative of social anxiety and speech delay. He was highly anxious and upset if I needed to leave him with another caregiver. He spoke only two or three words by eighteen months of age, and he was very slow to warm up to other children whom he did not know. His grandparents were the only other caregivers who could watch him besides my husband and me. At age two, concerned with his limited progress, I consulted his pediatrician and began looking at intervention services. We continued to monitor him for the next year, and at age three he was diagnosed with developmental delay with receptive and expressive speech delay. He was enrolled in the early intervention developmental preschool class through our local school district where he attends school four days a week.

Now at age five, he has made remarkable progress in speech development, socialization, and adaptive behaviors within the classroom environment that he has shared with the same peers for two school years. That being said, he is still a minimum of one year behind his peers in basic speech and continues to have pervasive social delays with anyone who is unfamiliar to him. As we begin the transition from preschool to kindergarten this fall, he is currently undergoing neurodevelopmental assessment at our local children's hospital; full cognitive, speech and adaptive testing with the school district; and his assessment team is discussing a diagnosis of Pervasive Developmental Delay-Not Otherwise Specified (PDD-NOS). While he does not meet full criteria for ASD, he does have a significant language delay coupled with a pervasive social delay. It is believed that he will spend the majority of his kindergarten year (and perhaps thereafter) in the Intensive Resource Room (IRR), which is a special education resource room for the children who need the most intense one-on-one assistance. This transition is one that my husband and I have spent a great deal of time considering and praying about. Not only will our

son be moving from the trusted preschool classroom environment he has known for two years, he will also be moving to another school entirely, as our particular school district only offers preschool in one location and that location differs from where our son will attend K-5.

Also within the past year I have been accepted into a full-time doctoral internship at an in-patient psychiatric facility. This internship will be carried out during my son's kindergarten year, during which time I will also have one child in preschool and one child at home. As we plan for the upcoming year, I stare at the calendar as a mother with a developmentally delayed child; a child who is still undergoing evaluations to pinpoint a diagnosis; a child who is transitioning into a new school; a child who is highly anxious when left with unfamiliar adults; and two other children who require all the same love and attention that any young child needs. The distinct needs of my family's situation were, once again, incompatible in my mind with any of the childcare programs in our area. After searching and exploring the programs available, we have arranged for our family to come live with us for the year to help with childcare. This arrangement is one that will work out best for the children, but it's also an arrangement that could crumble at any moment if anything goes wrong with our family's day-to-day life at home that would prevent them from being able to commit to a one-year move. So here I sit, a mother who is holding her breath and praying for the stars to align and all to go as planned.

The richness of experiencing first-hand what it is like to raise a child with developmental delay, or to be a parent in search of an early intervention program for my own disabled child, brought clarity to the research in ways that otherwise would not have been possible. The idea that "all is data" was particularly salient to me as I frequently found myself writing memos as I processed my own experiences throughout the week. As my journey with my own son began to evolve, I came to meet criteria for participation in my own research and after careful discussion

with my committee, I made the decision to become an official participant. When deciding how I would go about telling my story, I considered having someone interview me but ultimately opted to write my story instead. I used data processing software, typed out the research question, and gave myself the liberty to write unbidden. It was the first time I had ever written about my experience as a mother in this situation and it was moving to read back through my notes as I moved into the coding stage of my interview data.

My personal experience as a parent in this situation was somewhat of a mix of several participants. When my son was first born, I felt as though I had little choice in what I wanted to do with my career. As a new mother, part of me was thrilled to stay home with my baby, but I also felt somewhat hesitant to give up a well-established job that I enjoyed. Over time, as I considered going back to work and my son began to show increasing signs of a delay, I came to accept the fact that a career was secondary to his needs, and until I found a childcare provider who could, without a doubt, meet his needs, I would not be returning to the work force. This time of acceptance came during data analysis and I found myself able to identify with the primary caregiver experience of several participants. I was also able to appreciate the financial impact to the family and the resourcefulness of parents to make ends meet. Near the end of data analysis my son was evaluated by the local school district's Child Find Program and received an IEP to begin developmental preschool. We noticed a difference in his behaviors and language within the month and at that point in time I remember a desire to speak with certain participants again and tell them "it does get better, hang in there." I did not act on this desire but did memo and reflect upon this experience of wanting to send hope. That experience was somewhat short lived, as the every-day demands of my life as a mom, wife and graduate-student presented issue after issue that required thorough planning and consideration for how to meet demands and deadlines while

raising a child with special needs. And so again, I found myself cycling between the mixed experiences of several participants where at some points I felt like I had a choice, and then at others I had none. It has been my personal experience, thus far, that raising a child with special needs is a cycle of ups and downs, and as a parent I must dig in my heels, commit to spending as much time in the trenches as necessary and take on the world to make sure my child's needs are met. While I cannot completely separate my personal experiences and bias from the research, I have strived to stay true to the data and allow for the emergence of a theory that is grounded in the combined experience of all participants, including my own.

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Appendix A:
Recruitment Announcement

Recruitment Announcement

Finding Childcare for the Disabled Child: The Process and Decisions through the Primary Caregiver's Lens

Are you raising a child with special needs? Is your child four years old or younger? Are you currently looking for childcare or have previously looked for childcare in the past two years?

The purpose of this study is to better understand what it's like to be a primary caregiver who is looking for childcare for a child with special needs. This process is one that most people cannot relate to or understand unless they have a child with special needs. I will interview primary caregivers about how they found a childcare placement to meet their child's learning needs. I want to understand how primary caregivers make decisions regarding their disabled child's placement in a childcare center.

If the following describe you and your child you could be included in the study:

1. You are currently looking for childcare, or have previously looked for childcare in the past two years.
2. Your child has a developmental delay that is likely to impact thinking, learning, or memory.
3. Your child is between the ages of 0-4 years.
4. You and your child live in Washington State.

Thank you for helping with this study. Participants who meet eligibility criteria and complete the single scheduled interview will receive a small token of appreciation in the form of a \$10 gift card from Starbucks. If you are interested in participating in the study, please contact me by (date to be determined depending on how soon I obtain HSC approval) at the email address or phone number listed below.

Appendix B:
Preliminary Phone-Screening Questionnaire

Preliminary Phone-Screening Questionnaire

Childcare for the Disabled Child: the Process and Decisions
through the Primary Caregiver's Lens

“Hi, may I please speak to XXXXXX?”

If potential subject is available, Begin Screening Below

If potential subject is not available:

“May I leave a message for him/her?”

No: “Okay, when might be a good time to reach him/her? Okay, I’ll try back then.”

Yes: "Thank you. My name is Misty Torres and I am calling from the School of Applied Psychology at Antioch University. Please let him/her know that he/she can call me back at any time at.... Thank you" [wait for person to take number, repeat telephone number if necessary]

Screening

“Hi! Is this, (potential subject’s name)?”

“My name is Misty Torres from the School of Applied Psychology at Antioch University; I am returning your call regarding the Childcare for the Disabled Child study. Is this a good time to talk about the study?”

No: “Okay, when would be a good time to call back? [Wait for reply] Thanks, I’ll call back then.”

Yes: “Okay, let me tell you a bit about the study. To determine if this study is a good fit for you, I need to ask you some screening questions about your experience with childcare for disabled children. This screening includes 4 questions such as, ‘Does your child have a developmental delay that is likely to impact thinking, learning, or memory. Is it ok if I go ahead and ask you these questions now?’” [*Pause and wait for confirmation*]

Yes: Great, let’s get started.

Question	Yes	No

1. Are you the primary caregiver of a child with a developmental delay that is likely to impact thinking, learning, or memory?		
2. Is your child between the ages of 0-4 years?		
3. Do you and your child currently reside in Washington State?		
4. Are you currently looking for childcare, or have you previously looked for childcare in the past two years?		

“Thank you for answering these questions.”

No: Would you prefer I call at another time to ask these questions?

Yes: Okay, what time would work for you? Great, I’ll call you back on [repeat time and day]. [Get contact information and record.]

No: These questions are necessary to determine if this study is a good match for you. Perhaps you would like some more time to consider being in this study. If you are interested in the study, please call me back at this number. Thank you for your time.

If not eligible: “I’m sorry. Based on your answers, this study would not be a good fit for you. Thank you very much for your time.”

If eligible: “From your answers it appears that you meet the eligibility criterion for the study.”

Then, “To start, I would like to send you a consent/assent form describing the study. I would like you to read the form carefully, and to sign if you are willing to participate in the study. Would you like to receive the form by mail or by email?”

If by mail, get potential participant’s address.

If by email, say: “You should know that I cannot guarantee confidentiality for email communication. Feel free to use email to get in touch with me or to ask a question, but please do

not use email to communicate any personal information about yourself or others.”

Get potential subject's email address.

“So, once you receive the consent/assent form, you will need to read and sign it. If you have any questions about participating in the study or about the consent/assent, you can call me directly. My telephone number will be on the consent/assent form. If you decide to participate, I will collect the consent/assent form when we meet in person for your interview.

“Do you have any questions about the study?”

If yes, answer questions.

If no: “Let me give you my contact information just in case you have questions after we are done talking today. My phone number is..... You can also email me at However, please remember I cannot guarantee confidentiality of email.”

“I will send out the consent forms to you today. Is it okay if I call you on XXXXX [suggest a date five days from the current date] to make sure you received them and to schedule your interview?”

If yes: “Great thank you. I will follow up with you on XXXX to make sure you received the forms and to schedule your interview.”

If no: “Okay, then if you decide to participate, please call or email me when you have completed the consent forms so that we can arrange our first meeting. Good bye.”

Appendix C:

Antioch University Seattle Informed Consent Form

Antioch University Seattle Informed Consent Form

The Psy. D. Program supports the practice of protection for human subjects participating in research and related activities. The following information is provided so that you can decide whether you wish to participate in the present study. You should be aware that even if you agree to participate, you are free to withdraw at any time, and that if you do withdraw from the study, you will not be subjected to reprimand or any other form of reproach.

Interviews will be held at your local library and will be recorded for the purpose of transcription. Immediately following the interview, each interview shall be transcribed verbatim. The researcher reserves the right to hire a transcriptionist if it's determined to be necessary. The research materials (i.e., your preliminary screening questionnaire, the tape-recorded interview, and the interview transcript) will be kept in a secure locked location accessible only to the researcher for a period of no less than one year.

Description of risks to be expected from the study or research:

The purpose of this study is to better understand the process of selecting a childcare placement for a child with special needs. While participating in this study it is possible that you will experience any number of emotions ranging from invasion of privacy, embarrassment, frustration, negative self-labeling, to disappointment.

Description of benefits to be expected from the study or research:

This study could potentially lend important information regarding the challenges that caregivers face as they make decisions regarding their child's placement in a childcare setting. Specifically, the mental health community could learn what primary caregivers have learned regarding their child's developmental delay; what types of resources are currently available to aid them in their decision; what types of resources they would like to see made available; and

how their decisions have impacted the day-to-day life of their entire family. Information such as this is valuable from a community standpoint as it gives psychologists, as educators in the mental health field, a tangible list of issues that merit further development within the community.

Participants who meet eligibility criteria and complete the single scheduled interview will receive a small token of appreciation in the form of a \$10 gift card from Starbucks.

I have read the above statement and have been fully advised of the procedures to be used in this project. I have been given sufficient opportunity to ask any questions I had concerning the procedures and possible risks involved. I understand the potential risks involved and I assume them voluntarily. I likewise understand that I can withdraw from the study at any time without being subjected to reproach. I may also request the researcher provide me with a copy of the summary data results at the conclusion of the study. To receive a copy of the summary data I agree to provide the researcher with a mailing address at which I can receive said data.

Signature _____ Date _____

Subject and/or Authorized Representative

Signature _____ Date _____

Subject and/or Authorized Representative

Appendix D:
Statement of Confidentiality

Statement of Confidentiality

By signing this document, I acknowledge that I _____, have been hired by Misty D. Torres for the purpose of data transcription. I understand the data I am transcribing relates to Mrs. Torres' doctoral dissertation and is to be held in the highest level of confidence.

By signing this document I also agree to the following:

1. Agree to respect and maintain the strict confidentiality of all data I am given access to for the purpose of transcription.
2. Agree not to copy, disseminate, or publish the data for any reason other than to provide a verbatim transcription of the data to Mrs. Torres.
3. Agree to return all audiotapes to Mrs. Torres immediately upon completion of the data transcription.

Print Name

Signature

Date