

A PHENOMENOLOGICAL EXPLORATION OF PARENTS' PSYCHOLOGICAL
EXPERIENCES OBTAINING A DIDAGNOSIS AND ACCESS TO SERVICES
FOR THEIR CHILDREN WITH AUTISM SPECTRUM DISORDER

by

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DISSERTATION ABSTRACT

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Title: A Phenomenological Exploration of Parents' Psychological Experiences Obtaining a Diagnosis and Access to Services for Their Children with Autism Spectrum Disorder

The three primary purposes of this study were to (1) acquire knowledge of parents' psychological experiences obtaining a diagnosis and accessing services for their child with ASD by examining the actual situation, as lived through and experienced by the parents, (2) gain knowledge of the meaning of advocacy and empowerment from parents who are living these experiences, and (3) derive possible implications for enhancing services provided by mental health professionals, service providers, and policy-makers to parents of children with autism. I utilized a sequential transformative integrated design, drawing data in Wave II of a larger, on-going investigation examining child, family, and community variables associated with early identification and treatment of autism spectrum disorders in the Pacific Northwest. I conducted a descriptive exploratory analysis to describe all participants from Wave II with respect to measures of sociodemographic variables, parental satisfaction with services, family empowerment, and reported relationships among these variables. Next, I conducted in-depth semi-structured interviews with six participants identifying as low-income and/or ethnic minorities to explore their experiences throughout the process of obtaining a diagnosis

and accessing services for their child with ASD. Interviews were recorded and transcribed.

Data were analyzed using a phenomenological reduction and integrated with quantitative results. Constituent elements of the parent experiences included, but were not limited to: a desire and/or appreciation for sources of support and information regarding services; engaging in ongoing research and networking to learn about services; a need to be the expert on their child; and fear regarding availability of future services and child's future after parents die. Constituent elements of empowerment and advocacy showed that these were conceptually and experientially related to one another, such that advocacy functioned as a behavioral manifestation of empowerment for parents in this study. Findings contribute to the literature on family experiences with the diagnostic and service utilization processes for ASD. Findings are discussed in regards to recommendations and implications for mental health professionals, service providers, and policy-makers working towards fostering more supportive and equitable diagnostic and service utilization pathways for these families.

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This dissertation is dedicated to the six strong, patient, amazing mothers that shared their stories with me, and to all caregivers of children with ASD and DDs, may this work help us do a better job serving you.

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CHAPTER I

INTRODUCTION AND RESEARCH PROBLEM

The purpose of this study was to acquire knowledge of parents' psychological experiences (Giorgi, 2009) obtaining a diagnosis and accessing services for their child with autism spectrum disorder (ASD) by examining the actual situation, as lived through and experienced by the parents. Knowledge generated from this inquiry has resulted in insights regarding these parents' experiences that can inform parents of children with ASD, service providers, and policy makers.

This chapter begins with a brief overview of the background and context framing this study. This chapter continues with the problem statement and accompanying research questions. Following the research questions is a discussion about the research approach, researcher perspectives and assumptions, rationale and significance of the study, and key terminology.

Background and Context

Autism spectrum disorders are the fastest growing group of neurodevelopmental disorders in childhood, affecting an estimated 1 in 68 children in the United States (Developmental, 2014). Compared to children with other specialized healthcare needs, children with ASD are underserved, with more delayed healthcare, less family-centered care, and more difficulties with referrals (Kogan et al., 2008; Lord & Bishop, 2010). Families of children with ASD have more financial problems, provide more than 10 hours a week of healthcare coordination for their children, and are more likely to stop or reduce work than families of other groups of children with special needs (Honberg, Kogan, Allen, Strickland, & Newacheck, 2009; Kogan, et al., 2008; Lord & Bishop,

2010). Providing intensive early intervention is critical to maximizing outcomes for children with ASD (Woods & Wetherby, 2003).

Problem Statement

Research indicates that significant numbers of parents experience difficulties with the ASD diagnostic process and accessing available services (Goin-Kochel et al., 2006; Wiggins, Baio, & Rice, 2006). Many parents report negative experiences as they seek a diagnosis, including long wait times, feeling disrespected, isolated, confused, and frustrated with current diagnostic and service utilization pathways (Ahern, 2000; Mulligan, MacCulloch, Good, & Nicholas, 2012; Schall, 2000). Furthermore, research indicates that these pathways are not equitable, such that parents from ethnic and racial minority backgrounds and those from low SES backgrounds are likely to face more obstacles in obtaining a diagnosis and accessing services than those from higher SES and European American groups. At present, there is a lack of research designed to explore and understand the psychological experiences of parents going through these processes. This information is crucial to affecting systemic change that results in more supportive and equitable diagnostic and service utilization pathways for these families.

Purpose of Study and Research Questions

The purpose of this research was to acquire knowledge of parents' psychological experiences obtaining a diagnosis and accessing services for their child with ASD by examining the actual situation, as lived through and experienced by the parents. I was also interested in gaining knowledge of the meaning and function of advocacy and empowerment for the parents going through these experiences. Furthermore, I was interested in utilizing the acquired knowledge to draw implications for mental health

professionals, service providers, and policy-makers. In order to explore and understand the phenomenon under investigation, the central question guiding this study asks, what is the lived psychological meaning of parents' experiences going through the diagnostic and service utilization process for their child with ASD? Two subquestions also guide the study. The first is, what is the psychological meaning of advocacy in the context of parents' experiences going through the diagnostic and service utilization process for their child with ASD? The second asks, what is the psychological meaning of empowerment for parents' going through the diagnostic and service utilization process for their child with ASD? Additional procedural questions, that is, method-related questions asked at each step of the analysis and synthesis, are discussed in Chapter III.

Research Approach and Design Overview

With the approval of the University of Oregon's Institutional Review Board, I studied parents' experiences with diagnostic and service utilization pathways for their children with ASD. The study utilized a sequential transformative integrated design with unequal priority to quantitative and qualitative analyses, such that while a quantitative descriptive analysis was implemented first, priority was given to the descriptive phenomenological qualitative analysis [represented as quan → QUAL]. Sequential transformative integrated designs are particularly useful for giving voice to diverse or alternative perspectives, advocating for research participants, and better understanding a phenomenon (Hanson et al., 2005).

This study drew data from Wave II of a larger, on-going investigation examining child, family, and community variables associated with early identification and treatment of autism spectrum disorders in the Pacific Northwest (Early Autism Project; PI,

McIntyre; see also McIntyre & Barton, 2010). Participants were recruited for Wave I of this study through community clinics and organizations. For Wave II, participants from Wave I were contacted and asked to participate in follow-up interviews. Families that agreed to participate were asked if they would like to be included in the present study. Data collection for Wave II began with structured interviews conducted by members of the research team for the Early Autism Project, including the author of this dissertation. Using quantitative data collected via these interviews, a descriptive exploratory analysis was conducted to describe all participants from Wave II with respect to measures of sociodemographic variables, parental satisfaction with services, family empowerment, and relationships among these variables.

I then utilized purposeful sampling to follow-up with six participants identifying as low-income with respect to the rest of the Wave II sample in order to invite them to participate in subsequent interviews regarding their experiences throughout the process of obtaining a diagnosis and accessing services for their child with ASD. Semi-structured interviews were recorded and transcribed verbatim and then analyzed using a scientific phenomenological reduction as described by Giorgi (2009; 2012), slightly modified as outlined by Finlay (2012) and Wertz (2005). In brief, this type of analysis involves reading the data, bracketing out assumptions and past knowledge, reducing the data to “meaning units,” or meaning parts, organization and expression of the data from a psychological perspective using free imaginative variation, and synthesis and summary of the data. During the synthesis and summary phase, I integrated the quantitative data with the phenomenological qualitative data. This process is elaborated in Chapter III.

Assumptions

Based on my experiences as a therapist in the community and as a data collector for Wave I of the Early Autism project, I made three primary assumptions during the conceptualization and design of this study. First, most parents of children with ASD living in the community from which data was collected were not generally satisfied with the diagnostic and service utilization process. This assumption was based on results Wave I analyses as well as statistics illustrating that the quality of services available in the community were far below the best practice guidelines (Downs & Downs, 2010; Hidalgo, McIntyre, & McWhirter, 2015).

Second, participants are embedded within multiple interacting ecosystems (i.e., a microsystem, mesosystem, exosystem, macrosystem, and chronosystem), and reciprocal interactions occur between the participants and their environmental settings (Bronfenbrenner, 1979, 1989). Consequently, participants are active in their environmental settings, communication between ecosystems is bidirectional, and changes in one environmental setting affect changes in subsequent ecosystems (Bronfenbrenner, 1979, 1989). Individuals may vary in their awareness of their own risk and protective factors as well as the extent and limitations of their own agency.

Third, my assumption was that high levels of critical self reflection and empowerment, or the ability to perceive and take action against oppressive social, political, and economic elements of society has the potential to support parents and families with children with ASD in developing resiliency, increasing advocacy efforts, and affecting systemic change (Cattaneo & Chapman, 2010; Freire, 2005; McWhirter, 1997).

Researchers engaging in a scientific phenomenological reduction must, to the best of their ability, bracket out, or suspend any assumptions and previous knowledge of the subject matter in order to better describe the participants' experiences with as little researcher bias as possible (Wertz, 2005). These assumptions can then be reintroduced during the data synthesis and summary phases of analysis.

The Researcher

At the time of conducting this study, I was enrolled in a counseling psychology doctoral program, with three years of experience as a therapist in the community from which participants were drawn. In addition, I had four years of experience collecting data as part of the Early Autism Project, interacting with some of the participants during Wave I and Wave II data collection.

As much as these experiences were valuable in preparing me for the present study and providing insight, they may serve as a liability, biasing my judgment in research design and data synthesis and summary. I engaged in ongoing critical self-reflection using two strategies: journaling and dialoguing with professional colleagues and advisors. These activities functioned as a means for me to continuously reflect on potential sources of bias influencing my research methods and data synthesis.

Rationale and Significance

The rationale for this study emanated from my desire to better understand parents' psychological experiences related to obtaining a diagnoses and accessing services for their child with ASD. There is a dearth of studies exploring this phenomenon, and few studies do so using phenomenology. At the time the analysis was underway, there were

no published studies examining this phenomenon using a transformative phenomenological design with an explicit advocacy lens.

Family experiences with the diagnostic and service utilization processes may set the stage for how parents proceed with treatment options for their child and how they develop relationships with professionals. Thus, examining these experiences may yield valuable information for improving the service delivery system for families of children with ASD. On a larger scale, findings may help professionals and policy makers to work towards supporting equitable diagnostic pathways for parents and children in underrepresented and underserved sociodemographic groups.

Language Use Conventions

In this study, the pronouns “they/their/theirs” will be used instead of “he/she/his/hers,” unless referring to a specific individual that identifies as male or female. The use of “they/their/theirs” for both plural and singular subjects is an act of inclusion and acceptance of different gender identities, and an acknowledgement that gender is not binary. Additionally, Foertsch & Gernsbacher (1997) found that using the singular “they” in academic writing is both a more gender inclusive and a cognitively efficient substitute for the generic “he or she”.

In this study, the terms “parents” and “caregivers” are used interchangeably. While the definition of “parents” has previously evoked a heteronormative image of a mother-father dyad, this study will use “parents” the same way “caregivers” is used- to describe any person or set of people that are responsible for raising and caring for a child. The use of “caregivers” acknowledges that not all children are cared for and raised by biological parents.

CHAPTER II

LITERATURE REVIEW AND CONCEPTUAL FRAMEWORK OVERVIEW

The purpose of this study is to examine and understand parents' psychological experiences obtaining a diagnosis and accessing services for their child with ASD. In this study, "psychological experiences" refers to subjectively dominated moments in the participants' descriptions of their lived experiences (Giorgi, 2012). In other words, the focus is given to participants' descriptions of their internal experiences (thoughts, emotions, sensations) as well as how they make meaning from these experiences. Additionally, using the terms "psychological experiences" and "psychological meaning" explicitly acknowledges that the author, a doctoral candidate in counseling psychology, analyzed data from the perspective of the field of counseling psychology (Giorgi, 2012). This critical review of the literature explores family experiences of obtaining an ASD diagnosis for their children as well as accessing and utilizing services. In light of this, three major areas of research were reviewed: (a) Prevalence rates and disparities in ASD diagnosis and service utilization; (b) Barriers and challenges in obtaining an early diagnosis and accessing services; (c) Emerging research on the impact of parental empowerment and advocacy. A review of the literature on diagnostic and service utilization pathways and corresponding family experiences provides an understanding of the context, barriers, and challenges families face in order to obtain a diagnosis and services for their child with ASD, as well as an understanding of factors that may facilitate family empowerment as they undergo these processes. Bronfenbrenner's ecological model (1989) is utilized to provide a framework for understanding and

organizing diagnostic and service utilization barriers across the multiple interacting systems of a families' ecology.

To conduct this selected literature review, I used multiple information sources, including books, dissertations, Internet resources, professional journals and periodicals. These sources were accessed primarily through PsycNET's online database. The key terms "ASD" and "autism" yielded 6,703 results on PsycNET's database. The following key terms were added in different combinations to narrow down the results: ASD, autism, sociodemographic, parents, family, diagnosis, diagnostic, services, service utilization, advocacy, empowerment, experiences, satisfaction, disparities, empowerment, and advocacy. Furthermore, only articles published within the last 25 years were reviewed.

This chapter begins with an overview of the ASD diagnostic and service utilization prevalence rates, followed by an overview of current diagnostic and service utilization pathways. Next, I discuss diagnostic and service utilization disparities, and then barriers to early diagnosis and service utilization across multiple systems. The next section describes the role of advocacy and empowerment in ASD diagnosis and service utilization pathways. In each section, I highlight gaps in the literature as well as relevant contested issues. Each section of the literature review closes with a synthesis and research implications. The chapter concludes with an interpretive summary that illustrates how the literature has informed my understanding of the material and how the material contributes to the ongoing development of the conceptual framework of the study. The last section of this chapter includes the research questions guiding this study.

ASD Diagnosis Prevalence Rates and Service Utilization

Autism spectrum disorders (ASD) comprise the fastest growing group of neurodevelopmental disorders in childhood, affecting an estimated 1 in 68 children in the United States (Developmental, 2014) and comparable numbers in Europe and the Western Pacific (Elsabbagh, et al., 2012). A diagnosis of ASD includes: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all referred to as autism spectrum disorder. ASD is marked by deficits in social functioning and interaction, language and communication, and appropriate play skills (American Psychiatric Association, 2013).

Data from the National Survey of Children's Health indicate that the prevalence of parent-reported ASD among children aged six to 17 years increased from 1.2% in 2007 to 2.0% in 2011–2012 (Blumberg et al., 2013). The increasing prevalence highlights a need for resources to provide care for this population of children and their families. While there is some evidence to support improved service utilization rates (Ruble, Heflinger, Renfrew, & Saunders, 2005), the increasing service utilization rates are not proportional to the increasing prevalence rates. Data collected from a state Medicaid Managed Care program from 1995 through 2000 revealed that the number of children with ASD who received services over time did increase significantly (Ruble et al., 2005). Despite the increase in service utilization, Ruble and colleagues (2005) found that between the fiscal years of 1995-2000, the rate of service use was only one tenth of what should be expected based on prevalence rates. Additionally, the number of service days provided per child decreased by about 40%. Service utilization rates for children with ASD are not increasing proportionately to the prevalence rates, despite a growing need for these services (Ruble et al., 2005). In order to better understand and address this

discrepancy, a closer examination of families' experiences obtaining a diagnosis and accessing services for their child with ASD is needed.

Diagnostic and Service Utilization Pathways

Several healthcare professional groups, including the American Academy of Pediatrics (Johnson & Myers, 2007) and the American Academy of Child and Adolescent Psychiatry (Volkmar, Cook Jr., Pomeroy, Realmuto, & Tanguay, 1999), have recommended specific protocols to be followed in an initial evaluation for a child suspected of having ASD. These nationally recommended practices are not used in most clinical settings, however. Developmental screening procedures vary widely among practitioners, and between one half and three quarters of physicians did not regularly use formal developmental screening tools for children under 3 years of age (Lord & Bishop, 2010; Sand et al., 2005; Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003). Physicians surveyed in these studies reported that lack of time, insufficient reimbursement, and staffing were major barriers to adhering to best-practice guidelines for clinicians. With such varied and unstandardized evaluative and diagnostic procedures, families' experiences undergoing these procedures with their child may be expected to vary, however, there are some common themes within these diagnostic and utilization pathways. Lord and Bishop (2010) provide the following example in order to illustrate what this process might be like for families:

One route to diagnosis might be through a primary care pediatrician, who after several brief visits during which the parent expresses concerns, refers a child at 18 months to a developmental pediatrician. The developmental pediatrician sees the child at 24 months after 6 months on a waiting list, suspects ASD, and refers the

child directly to a private practice that specializes in Applied Behavior Analysis (ABA) treatment. The family starts treatment quickly, but they are never told that the child likely has significant cognitive impairment and severe language delays in addition to autism. The family receives (and pays for) excellent in-home behavioral teaching but does not realize the scope of the child's problems until, at age 4, they attempt to enroll him in a regular preschool and are rejected because he has very limited understanding of language and is not toilet-trained (p. 6).

The authors describe another example of an alternate route to diagnosis:

In an alternative scenario, an astute pediatrician might suspect ASD in a 15-month-old child, but when she raises the possibility, the family is taken aback and does not return for a scheduled follow-up visit. At age 2, the child is asked to leave his second child care program because of behavior problems, and the parents take the child to a new pediatrician who refers the child to a psychologist who has difficulty testing her and raises the possibility of intellectual disability. At this point, the family hears about a local physician whose specialty is alternative treatments. ASD now seems like a more positive diagnosis than intellectual disability and they schedule an evaluation. After months of expensive tests, treatments, and supplements, the child, though bright, is 3 years old and has made minimal progress (p. 6).

It is important to note that each step in the series of assessments in both scenarios often involves months on waiting lists, confusion about what is and is not covered by insurance companies, and paying out of pocket for some of the services received (Filipek, et al., 2000; Harrington, Rosen, Garnecho, & Patrick, 2006; Lord & Bishop, 2010).

Families of children with ASD frequently experience difficulty obtaining a timely diagnosis, often waiting over a year and seeing an average of four to five different providers between initiating the evaluative process and finally receiving an ASD diagnosis (Goin-Kochel et al., 2006; Wiggins, Baio, & Rice, 2006).

Once children are diagnosed and begin utilizing services, families must navigate yet another confusing process of selecting and sometimes advocating for specific treatment options. Approximately 40% of families with children with ASD experience problems obtaining needed care from specialty doctors or difficulty accessing desired services (Kohler, 1999; Krauss, Gulley, Sciegaj, & Wells, 2003). According to data gathered between 2009 and 2010 from the National Survey of Children with Special Health Care Needs, parents of children with ASD experienced greater dissatisfaction with their health care provider and perceived suboptimal clinical care, less timely care, and more limited insurance coverage compared with parents of children with ADHD. Parents also reported less insurance coverage compared with parents of children with intellectual and developmental disabilities (Zablotsky, Kalb, Freedman, Vasa, & Stuart, 2014).

Goin-Kochel, Macintosh, & Myers (2006) found that children diagnosed with ASD received four to six different treatments simultaneously, noting that younger children often were provided more behavioral, educational, and alternative treatments while older children were provided more medication management. Treatment options and service utilization patterns change based not only on a child's age, but also on insurance coverage practices that change over time. Ruble et al. (2005) analyzed behavioral health data from a state Medicaid Managed Care program and found the most prevalent forms of treatment had changed from 1995 to 2000: day treatment was removed

entirely as a treatment option and medication and case management increased disproportionately to the number of children served. With changing trends in insurance policy coverage, parents' treatment options for their children with ASD are often dictated by their insurance company- the choice between limited options for covered or partially-covered treatments, or paying additional costs for other treatments parents believe will be most effective for their child.

In some cases, characteristics of ASD can be identified in children by 16 months of age, with signs evident in some children as early as nine months of age (Rogers & Vismara, 2008). It is possible to reliably diagnose ASD by 18 to 24 months of age (Johnson & Myers, 2007), however, on average, children identified with ASD in the U.S. were not diagnosed until after age four, indicating that diagnosis is unnecessarily delayed in many cases (Kleinman et al., 2008; Shattuck et al., 2009). Without a diagnosis, many children are not able to access early interventions in a timely manner. Furthermore, early diagnosis and intervention is associated with significantly better treatment outcomes (Woods & Wetherby, 2003). Next, I review literature on family experiences with diagnostic and service utilization pathways for their child. Experiences may differ significantly based on the child, the family, insurance coverage or lack thereof, and the resources and services available (Harris, Barton, & Albert, 2014).

Disparities in Diagnosis, Symptomatology, Access to Services, and Service

Utilization

Diagnostic disparities. Early identification of ASD is an important factor in accessing services and determining a child's eligibility for school and community-based interventions. Providing intensive early intervention is critical to maximizing outcomes

for children with ASD; evidence suggests that the earlier intervention begins, the better the outcome (Woods & Wetherby, 2003). There are diagnostic disparities in the United States and elsewhere among children with ASD as a function of sociodemographic variables, such as race, ethnicity, and socioeconomic status (SES; Croen, Grether, & Selvin, 2002; Elsabbagh et al., 2012; Liptak et al., 2008; Mandell, Listerud, Levy, & Pinto-Martin, 2002;). Research findings indicate that White children are diagnosed earlier than Black children, despite higher risk factors experienced for children born to Black mothers (Croen et al., 2002). After controlling for age, sex, and time eligible for Medicaid, Black children spent more time in treatment before receiving a diagnosis, and received a diagnosis an average of 1.4 years later. By age 5.5, 50% of White children had a diagnosis compared to only 28% of Black children. Furthermore, near-poor (household incomes at the poverty line to 100% above the poverty line) children received a diagnosis later than those with incomes 100% above the poverty level or those below the poverty level (Mandell, Novak, & Zubritsky, 2005). In a survey of families from five countries, higher levels of parental education and income were associated with earlier diagnosis of ASD (Goin-Kochel et al., 2006). Research utilizing data from the National Survey of Children's Health from 2003 to 2004 found that Latino families had lower prevalence rates than non-Latino families (5.1% v 2.6%) and that the lowest prevalence rates for preschool-aged children occurred in poor children (1.6%; Liptak et al, 2008). Despite this low prevalence rate of ASD for poor children, recent epidemiological studies suggest an increased risk for ASD among lower SES groups (e.g., Harris, 2012). Individuals from higher SES backgrounds are identified more often than their lower income counterparts (Durkin et al., 2010). Durkin and colleagues interpret these differences as an indication of

an underrepresentation of children with ASD from low and middle SES backgrounds in the U.S. and an overrepresentation of children in higher SES groups. They argued that parents with higher SES may be more likely to persist in finding a diagnosis to obtain services for their children, resulting in earlier diagnoses and higher prevalence rates. Along the same lines, this persistence in higher SES parents might result in more diagnoses of milder cases of ASD, which may in turn result in a higher prevalence of ASD in higher SES groups (Durkin et al., 2010; Harris, 2012). Noting that only limited data were available for low-income countries, Elsabbagh et al. (2012) did not find evidence that SES, geographic region, or cultural differences contributed to differing prevalence rates worldwide.

Symptom disparities. SES differences in the United States in ASD extend beyond risk, prevalence, and diagnostic rates. Mayes and Calhoun (2011) examined demographic predictor variables of ASD symptoms in a sample of 777 children aged 1-17 in the Northeast United States. The investigators found that autism severity did not differ by race or gender; however, behavior and mood problems were significantly more common in the lower SES group than the higher SES groups, controlling for gender and race. Specifically, in professional families, 86.8% of children had over reactivity, meltdowns, and/or aggression, in contrast to 94.2% in non-professional families. In professional families, 66.9% of children were described as moody or labile, in contrast to 81.0% in non-professional families. Liptak et al. (2008) also found that children from poorer families had more severe ASD based on parent report than children from families with higher household incomes. They also found that children from Latino families had more severe ASD symptoms compared to other ethnicity groups. More recently in the

U.K., Midhouse, Yogaratnam, Flouri, and Charman (2013) found that family poverty, low maternal warmth, and household chaos are risk factors for externalizing problems in children with ASD, contributing to more severe symptomatology. Taken together, this research indicates children from low SES families and who are members of ethnic minority groups had more severe ASD symptomatology than those from higher SES families and White families. Relatedly, parents of children with more severe ASD symptomatology report feeling less satisfied with the diagnostic process than parents with children with less severe ASD symptomatology (Lavelle et al., 2014; Moh & Magiati, 2012).

Disparities in access to services. Once diagnosed with an ASD, access to necessary services is lower for racial and ethnic minority families, families with low parental education, families living in nonmetropolitan areas, and families not following an empirically-supported treatment approach (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Similarly, Liptak and colleagues (2008) found that risk factors in the U.S., such as ethnic or racial minority status, living in poverty, and receiving health insurance based on poverty need, are each associated with less access to services compared to groups without these identified risk factors. In 2007, the Center for Disease Control and the Association of University Centers on Disabilities began working together to enhance states' capacities to respond to increasing demands for earlier identification, earlier diagnosis, and coordination of service systems for children with ASD and DDs. State committees highlighted that families that are low income, rural, and/or non-English-speaking encounter more challenges than others in accessing a diagnosis and early intervention services (Peacock & Lin, 2012).

These risk factors often co-occur, such as ethnic or racial minority status and poverty. Mandell and colleagues (2002) reported that Latina/o children with ASD in Philadelphia were less likely than White children to have health insurance, three times as likely to live in households that fall below the poverty line, twice as likely to lack a regular source of medical care, and 1.3 times as likely to experience difficulty accessing specialty care. The existing literature suggests there is an overlap between groups at higher risk of ASD and groups facing more barriers to accessing services. Close examination of family experiences in obtaining a diagnosis may yield findings important for professionals working with families and children with ASD, including how to better serve underrepresented groups.

Disparities in service utilization. Family characteristics can also influence types of services accessed and utilized. Irvin, McBee, Boyd, Hume, and Odom (2012) examined how child and family factors, namely, SES, caregiver race/ethnicity, and caregiver stress, affected service receipt for 137 preschool-aged children with ASD and their families in U.S. schools and private settings. For those receiving school-based services, students with Latina/o caregivers received significantly less speech-language therapy (SLT) and occupational therapy (OT) than students with White caregivers; students with Asian caregivers received significantly less OT than students with White caregivers. For those receiving private therapy services, higher SES was associated with higher probability of receiving OT compared to lower SES families. Lastly, higher SES was associated with a higher likelihood of receiving treatments based on the principles of applied behavior analysis (ABA), one of the most studied and empirically-supported treatments for ASD (Cooper, Heron, & Heward, 2007). Thus, family SES and

race/ethnicity were associated with the type and dosage of services used. Similarly, Thomas and colleagues (2007) examined the effects of race and ethnicity on access to developmental services and found that racial and ethnic minority families had half the odds of working with a case manager, and only one fourth the odds of working with a psychologist, developmental pediatrician, and/or sensory integration therapy. Another study revealed that Latina/o children recently diagnosed with ASD were six times more likely than children of other ethnicities to use nontraditional treatments, and often these treatments had little to no evidence of efficacy. One limitation of studies examining sociodemographic disparities, however, is not all studies explicitly control for the fact that White families are more likely to be in high SES groups than Latino and Black families (Irvin et al, 2012). Irvin and colleagues speculate higher SES families may be in a better position to advocate for their child to receive higher dosages and specific treatments, such as those based on the principles of ABA, than parents in the lower SES groups. If more high SES families are also White, differences in treatment type and dosage could also be due to cultural factors or ethnic/racial bias among service providers, leading to different family experiences during the diagnostic and service utilization process. Because of the disparities operating on multiple systemic levels for families from low SES and ethnic minority backgrounds, these families will be considered and referred to as oppressed and underprivileged groups in the present study.

Barriers and Challenges to Service Utilization Across Ecosystems

Srebnik, Cauce, and Baydar (1996) define barriers to general service utilization as “social and environmental constraints that can occur at the individual, community, or broader political level” (p. 215). I will situate Srebnik and colleagues’ definition of

barriers within Bronfenbrenner's (1989) ecological model, a heuristic framework that suggests that individuals are imbedded in multiple interacting ecosystems (i.e., a microsystem, mesosystem, exosystem, macrosystem, and chronosystem). This ecologically contextualized definition will serve as the operational definition of barriers in this discussion. The ecological model assumes that individuals are active in their ecosystems, influence between ecosystems is bidirectional, and changes in one ecological system affect changes in other ecosystems (Bronfenbrenner, 1989). When this definition of barriers is applied to an overview of how parents with children with ASD access services and obtain a diagnosis, barriers and challenges across a family's ecology can be thoroughly identified and discussed. The following paragraphs will utilize Srebnik and colleagues' definition of barriers and challenges across the ecological model to organize and review the existing literature on this topic for families as they undergo the diagnostic and service utilization processes.

Sociodemographic barriers. SES disparities in diagnosis, access, and service utilization have been described. These disparities exist at multiple levels of the ecology. At the family level, sociodemographic group membership can affect each family's diagnostic and service utilization experience. One mixed-methods study found that parents of children with ASD with higher household incomes were more likely to report being satisfied with the care received by their child's pediatrician than parents of children with ASD with lower household incomes (Hidalgo et al., 2015). On a larger systemic scale, patterns exist such that racial and ethnic minority families, those living in nonmetropolitan areas and those with limited education achieve only limited access to care for ASD (Thomas et al., 2007). In addition, a family's SES can make a significant

difference in the intervention planning, education, technology utilization, and support services provided to a child with ASD. SES also affects access to regular health care and directly impacts whether or not a child gets specialized training and support (Ennis-Cole, Durodoye, & Harris, 2013).

Economic barriers. One of the most frequently cited barriers to service access and utilization across different ecological systems is financial strain (Lavelle et al., 2014). At a family-system level, studies have shown that families of children with ASD face high out-of-pocket costs (Kogan et al., 2008; Parish, Thomas, Rose, Kilany, & McConville, 2012) and productivity loss (Buescher, Cidav, Knapp, & Mandell, 2014). Reports from both the United States (Ganz, 2007) and the United Kingdom (Knapp, Romeo, & Beecham, 2009) have estimated costs to families of more than \$3–5 million dollars beyond the ordinary lifetime costs of raising a child without special needs. According to a national survey in the U.S., 78% of families with a child with autism reported having health care expenditures for their child for the prior 12 months. Among these families, 54% reported expenditures of more than \$500 out of pocket (Parish, 2012).

Compared to families of children with other special needs, families of children with ASD report more financial problems and are more likely to stop or reduce work (Honberg, Kogan, Allen, Strickland, & Newacheck, 2009; Kogan, et al., 2008). Kogan and colleagues (2008) found that families of children with ASD incurred higher health-related costs and took substantial time off work compared with families of children with other special health care needs. Additionally, parents of a child with ASD younger than 18 years work an mean of seven hours per week less than parents with children without

ASD, potentially resulting in significant yearly income loss and higher financial strain than families without a child with ASD (Cidav, Marcus, & Mandell, 2012). These findings indicate that parents of children with ASD may face significantly more financial strain when compared to parents of typically developing children as well as parents of children with other special health care needs. Within the population of families of children with ASD, a significant positive correlation has been found between ASD symptom severity and higher caregiving time costs, indicating this group may face the most financial strain overall (Lavelle et al., 2014).

On a broader systemic level, the societal costs of caring for children with ASD is significantly higher than caring for a child without ASD (Buescher et al., 2014; Lavelle et al., 2014). Research utilizing data from the 2011 National Health Interview Survey estimated the annual costs of caring for children aged 3 to 17 years, with and without parent-reported ASD. After controlling for child gender, age, race/ethnicity, insurance status, household income, country region, urban/suburban classification, and non-ASD-related illnesses, the additional costs of caring for a child with parent-reported ASD, including health care, education, ASD-related therapy, family-coordinated services, and caregiver time, totaled \$17,081 per year. Further analysis revealed ASD was associated with \$3,020 higher health care costs and \$14,061 higher aggregate non-health care costs. These non-health care aggregate costs included \$8,610 in higher school costs. This highlights that costs accrued outside of the health care system, specifically, costs associated with school-based services, account for the majority of the financial burden. In this study, out-of-pocket costs were not significantly higher for the ASD group, which is not consistent with other studies. Given the prevalence rates for children aged 3 to 17

living in the U.S. with ASD, the total societal cost of caring for this group of children was \$11.5 billion in 2011 (Lavelle et al., 2014). A similar study utilizing data from the existing literature in 2013 estimated the total cost of supporting an individual with an ASD and an intellectual disability during their lifespan to be \$2.4 million in the U.S. and \$2.2 million in the U.K. The cost of supporting an individual with an ASD without intellectual disability was \$1.4 million in the U.S. and \$1.4 million in the U.K. In addition to examining lifetime cost based on comorbidity with an intellectual disability, the authors also examined cost components based on age group. During adulthood, residential care or supportive living accommodation and individual productivity loss contributed the highest costs. Medical costs were also much higher for adults than for children (Buescher et al., 2014). The largest cost components for children were special education services and parental productivity loss. These results highlight the economic burden placed on school systems, as well as the need for policies that ensure schools have resources to provide needed services for their students.

ASD identification and diagnostic evaluation barriers. At a family-systems level, parents with children with ASD often report experiencing a lengthy, complex, and discouraging assessment and diagnostic process that results in parents feeling frustrated, confused, disempowered, and overwhelmed (Ahern, 2000; Mulligan et al., 2012; Schall, 2000). Some common themes arising from a phenomenological study examining parents' experiences during the diagnostic process include: initial recognition that 'something is different'; waiting, worry, and uncertainty; preference for diagnostic information in a hopeful tenor; feeling overwhelmed with information and emotion at diagnosis; processes of grief, relief, and making sense of ASD (Mulligan et al., 2012). Another qualitative

study examining parents' experiences during the diagnostic process for their child with ASD found that a common theme was parents' desire for coordinated services before, during, and following their child's diagnosis, as they had difficulties "navigating the system" (Martos, 2013). Other studies have found that another common experience is that some physicians tend to minimize or dismiss parents' concerns about their children. Despite the fact that child outcomes are most favorable when early, intensive interventions are provided, these physicians often instructed parents to 'wait and see,' leaving parents feeling frustrated and resentful with the diagnostic process (Ahern, 2000; Schall, 2000). Results from a thematic analysis of the Wave I data with a small sample of parents of children with ASD living in the Northwest indicated 78% of families interviewed had faced challenges with service delivery from medical professionals, primarily their child's pediatrician, during the diagnostic evaluation and service utilization process (Hidalgo et al., 2015). In the same study, 54% of families expressed that the pediatrician or other medical professional was a barrier to obtaining an earlier diagnosis. The most common specific complaints regarding medical professionals were that pediatricians "don't listen to parents," and "didn't validate [parents'] concerns" (Hidalgo et al., 2015). Delays in early identification have detrimental effects on the child receiving early and appropriate intervention. Consequently, parents are often dissatisfied with the process in obtaining an ASD diagnosis, which can contribute to the stress and caregiver burden that these families often experience (Howlin & Moore, 1997; White, & Roberson-Nay, 2009).

There is a dearth of studies examining family experiences receiving diagnostic evaluations and services, and even fewer studies that examine barriers that impact

parental satisfaction based on sociodemographic, or family-level variables. One cross sectional study of 494 families with children with ASD included families in six countries: the U.S., Ireland, England, Australia, New Zealand, and Canada (Goin-Kochel et al., 2006). Higher levels of parental education and income were associated with earlier diagnosis and greater satisfaction with the diagnostic process. Additionally, parents were more satisfied with the diagnostic process when they saw fewer professionals and obtained a diagnosis for their child at a younger age. That is, the higher the parents' level of education, the greater their family income, and the younger that children were when they received an ASD diagnosis, the more satisfied parents were with the process of getting a diagnosis. Another study focused on parental satisfaction during the diagnostic process for 102 Singapore families of children diagnosed with autism (Moh & Magiati, 2012). The parents most satisfied with the diagnostic process perceived a higher level of collaboration with professionals, found the information that they received to be more helpful, were less stressed, and their child diagnosed with autism had a lower severity of symptoms. The results of this study also indicated that parents from higher educational and socioeconomic backgrounds were more likely to raise concerns about their child's development at an earlier age than parents from lower educational and socioeconomic backgrounds.

As the studies above highlight, common themes exist in the experiences of these families, including high levels of stress, dissatisfaction, and confusion with the diagnostic process and health care providers. Individually cited family-level barriers follow particular themes, the results can be indicative of larger systemic issues. It is important to emphasize that in addition to pediatrician feedback (Martos, 2013) several other larger

systemic factors, including agency funding and staffing (Peacock & Lin, 2012) and social and community influences (Martos, 2013) can impact parents' experiences obtaining a diagnosis and accessing care.

On an broader systemic level, state representatives that attended a recent regional summit for the purpose of improving the identification, diagnosis, and coordination of services for children with ASD unanimously agreed that many parents, health care professionals, educators, and child care providers do not have access to adequate information about ASD. They also cited a lack of interdisciplinary training and professional development for the identification and diagnosis of ASD (Peacock & Lin, 2012). These concerns regarding the availability of information on ASD and the integration of services mirrors the finding that parents are more satisfied when they receive helpful information and perceive more collaborative relationships with professionals. Still, examining parents' experiences further could provide more insight into how to better address these concerns.

Service availability barriers. At the time of diagnosis, many parents are provided a range of literature, websites, and verbal recommendations for treatment. Some diagnosticians make strong recommendations for specific approaches while others provide a broad overview (Hebert 2014; Romanczyk & Gillis, 2005). Parents might also receive other recommendations from friends, teachers, etc., often leaving parents feeling overwhelmed and uncertain how to proceed (Hebert, 2014). One study that utilized an Internet survey to recruit 552 caregivers of children with ASD found that on average, caregivers use a total of seven different treatments (Green et al, 2006). Summed across all participants, participants endorsed having utilizing 110 different treatment options at

some point for their children with ASD (parents were allowed to add in options not already listed). Despite all the reported treatments being utilized, several of the options lacked empirical support. The third most commonly endorsed treatment, sensory integration therapy, currently lacks empirical support (Leong, Carter, Stephenson, 2014). Approximately 60% of parents surveyed endorsed utilizing alternative diets, medicine, therapies, and detoxification programs as treatment (Green et al., 2006). It is important to note, however, that because this study was an Internet survey, self-selection bias could lower the generalizability of findings. A recent qualitative study found that after their children's diagnosis of ASD, many parents expressed difficulties deciding which services to access first, difficulties understanding which service providers accepted their insurance, and a desire for more coordinated care (Martos, 2013).

One exploratory qualitative study conducted in the northeastern U.S. examined factors influencing parents' treatment decisions for their child with ASD. Results indicated the most frequently cited influences on treatment decisions were based on parents' personal attributes (personal experiences, perceptions/etiology of ASD, parenting style alignment with intervention, perspectives on children's learning, parental role, inner sense/gut), their children's attributes (age and developmental level, child's needs, intensity and severity of symptoms), and the attributes of the programs they considered (parents' perceptions of therapeutic approaches, intensity, physical environment, social environment, teachers, cost; Hebert, 2014).

Concurrent with evidence that parents tend towards utilizing multiple treatment options (Green et al., 2006), there is also evidence that parents perceive a lack of service and treatment availability (Goodwin, Intille, Albinali, & Velicer, 2011; Hidalgo et al.,

2015), which is again indicative of a larger systemic problem. Not only are parents reporting a lack of services, but they are also reporting difficulty accessing the ones that are available. In a poll conducted by Autism Speaks, three-fourths of parents reported that they are unable to access necessary medical, educational, and recreational services for their child with ASD (Goodwin et al., 2011). Furthermore, 83% of respondents said they had difficulty finding “appropriate” recreational activities and programs for their child with ASD (Goodwin et al., 2011).

Parents of children with ASD are not the only ones perceiving a lack in evidence-based services available. Peacock and Lin (2012) found that state representatives at a regional summit also reported a need for the development of effective, evidence-based interventions and model approaches. State teams also indicated a desire for more evidence-based interventions and suggested that program models must be developed, standardized, and implemented to improve health and education outcomes for children.

Summary. Several microsystemic factors influence the diagnostic and service utilization process, including sociodemographic variables and parental experiences, perspectives, and reactions (Bernier, Mao, & Yen, 2012). At the macro and exosystemic levels, factors that can help or hinder the process to early diagnosis and service utilization include: availability of services, societal acceptance, program funding and staffing, sociodemographic inequalities, and systemic bias (Bernier et al., 2012). It is clear that barriers to obtaining an early diagnosis and access to services exist, and that identifying and understanding these barriers for families is crucial to improving access to services and supporting equitable pathways. Furthermore, families’ experiences and levels of satisfaction with health care providers and services accessed can influence treatment

decisions and outcomes for their child with ASD, such that improving the process may lead to more positive relationships between families and health care and service providers, and in turn, lead to more positive treatment outcomes (Golnick, Maccabee-Ryaboy, Scal, Wey, & Gaillard, 2012; Thompsom-Kroon, 2012; Wooley, Stein, Forrest, & Baum, 1998).

Facilitative Factors: Advocacy and Empowerment

Given the often lengthy, confusing, stressful, and difficult process of obtaining a diagnosis and accessing services, the roles of parents with children with ASD have expanded to include the jobs of "information seeker, problem solver, committee member, public educator, political activist and, most importantly, spokesperson for the needs of their children" (Minnes, Nachshen, & Woodford, 2003, p.665; Nachshen, 2005). There is little research that examines how parents' navigate these processes effectively. One recent qualitative study examining family-level factors influencing parents' decision-making process when initiating the diagnostic process, and choosing or rejecting services for their child following a diagnosis of ASD, revealed that parents' perceptions of the severity of their child's symptoms proved to have the greatest impact on their ability to access and utilize services for their child, such that greater severity of perceived child symptoms related to greater access and utilization of services (Martos, 2013). The second greatest influencing factor, however, was the level of parents' resourcefulness and ability to actively seek treatments and interventions for their child (advocacy). "Outside influences," including family, social, and community supports also affected parents' ability to access and utilize services, as well as their decision-making in initiating the diagnostic process (Martos, 2013). There is emerging research that suggests parent-driven

“communities of support” can create lasting change in schools and communities in regards to availability and access to services for their child with ASD (Mickahail, 2010). These “communities of support” are described by the author as groups of parents that facilitate parental empowerment and advocacy for their child with ASD.

Empowerment. In the field of counseling, empowerment has been defined as “the process by which people, organizations, or groups who are powerless (a) become aware of the power dynamics at work in their life context, (b) develop the skills and capacity necessary for gaining some reasonable control over their lives, (c) exercise this control without infringing upon the rights of others, and (d) support the empowerment of others in their community” (McWhirter, 1991, p. 224). It involves awareness of social, political, and material resources and inequities in the environment, the strengths of individuals and communities, and the enhancement of well-being through support of the natural inclination to strive for positive change (Cattaneo & Chapman, 2010; Zimmerman, 2000). A focus on empowerment fits well with current dominant trends in the field of integrated health care such as strengths-based psychology and consumer-oriented care, as it encompasses a sense of personal control, which has been linked clearly to greater health and well-being (Cattaneo & Chapman, 2010). When applied to the specific challenges facing parents of children with DDs, the definition of empowerment is expanded to include a parent's active agency and sense of control not only for themselves, but also for their child and their family (Nachshen, 2005). Few studies have examined the process and effects of empowerment in parents of children with DDs, and even fewer have examined empowerment in parents of children with ASD.

Within this small body of literature examining parents of children with DDs, one study presented the development of a parent self-report measure of empowerment. Koren, DeChillo, and Friesen (1992) developed the Family Empowerment Scale (FES) to specifically measure level of empowerment in parents of children with intellectual and developmental disabilities. The FES is based on a framework of empowerment consisting of two dimensions: (1) the level of empowerment, and (2) the way that empowerment is expressed. Koren and colleagues suggest empowerment can occur at three levels: (a) Family; (b) Service System; and (c) Community/Political. For the second dimension, empowerment can be expressed in three ways: (a) Attitudes; (b) Knowledge; and (c) Behaviors. Using this scale, Weiss, MacMullin, and Lunskey (2014) found that in a sample of 156 mothers of children with ASD ranging in age from 4 to 21 years, empowerment was a partial mediator between child problem behavior and maternal distress. Specifically, greater child problem behavior was related to less parent empowerment, which was related to greater maternal distress. In a comprehensive literature review of empowerment research in health, education, and behavior, Van Ryn and Heaney (1997) found that family-centered services led to a greater sense of client empowerment as measured by scales of client self-esteem, feelings of control, sense of personal mastery. The authors also found that empowering professional-client relationships, characterized by interpersonal behaviors that enhance client self-esteem and feelings of control, are most effective in helping clients achieve specific goals.

Parents' level of family empowerment may be responsive to intervention. In one study, Minjarez, Mercier, Williams, and Hardan (2012) used the FES to measure empowerment in 17 families with children with ASD before and after participating in a

10-week therapy group. The group was designed to train parents to use pivotal response training (PRT; Schriebman & Koegel, 1996) with a specific focus on their children's language deficits. Results revealed significant changes from pre- to post-treatment, indicating that parents felt higher levels of empowerment and lower levels of stress after the intervention. One pilot study examined the effects of a six-session, co-facilitated support group for parents of children with ASD specifically focusing on advocacy skills and parent self-efficacy; statistically significant increases in the mean scores for the three subscales of the FES were found (Banach, Iudice, Conway, & Couse, 2010). Both of these studies were limited by small and fairly homogenous samples of well-educated families, however.

Demographic factors have been shown to play a significant role in the empowerment outcomes for parents of children with ASD. For example, one study examining the relationship between parent demographic factors and parental empowerment found gender and level of education were related to empowerment (Perry, 2013). In this study, empowerment was defined as a multi-dimensional process that helps people gain control over their own lives and was measured using the Psychological Empowerment Scale (PES; Zimmerman, 1995). The author found that mothers were more likely to report higher levels of empowerment (informal participatory behaviors regarding parenting a child with ASD) than fathers. Additionally, parents who had attended college reported higher levels of empowerment in regard to skills and knowledge (Perry, 2013). More research is needed to examine the experience, function, and effects of empowerment among different demographic groups. The results of these studies highlight the importance of family-centered, strengths-based approaches with

families to support family well-being and effective service delivery, and highlight the importance of more closely examining the role of family empowerment in accessing and utilizing services for a child with ASD.

Advocacy. According to Lee, Harrington, Louie, & Newschaffer, (2008), advocacy refers “to the process or act of arguing or pleading for a cause or proposal, either of one’s own or on behalf of someone else” (p. xvi). In a qualitative study of families with a child with ASD in Canada, Mulligan and colleagues (2012) found that themes associated with parents’ experiences obtaining a diagnosis included becoming an advocate, expert, and case manager. In addition, parents expressed a need for support, information, resources, and tools for navigating the complexity of service/treatments at the time of diagnosis.

In a qualitative analysis exploring advocacy, stress, and quality of life in a sample of 26 parents of children with developmental disabilities, Nachshen and Jamieson (2000) found that parents reported that advocacy decreased feelings of stress and improved quality of life when: (a) advocacy was perceived to be a coping mechanism, (b) advocacy efforts achieved positive outcomes, (c) professionals responded to advocacy in a positive and productive manner, (d) advocacy efforts were focused toward planning for the future, (e) parents were able to maintain a personal life, and/or (f) parents were not dealing with their own negative emotions, such as guilt and fear, regarding their child's disability. Increases in stress, however, were connected to: (a) parents' perception of advocacy as a challenge, (b) failure to achieve positive outcomes, (c) negative reactions from professionals, (d) a focus on past events, and/or (e) deleterious effects on personal functioning. Furthermore, Koren and colleagues (1992) found that parents' level of

empowerment , defined as the ongoing capacity of individuals or groups to act on their own behalf to achieve a greater measure of control over their lives and destinies, discriminated between parents involved in advocacy-related activities, such as advisory and political activities, and those who were not involved. Empowerment is linked with community activism, a necessary component to improving the lives of people with disabilities; therefore an important behavioral component of empowerment is advocacy (Nachshen, 2005). More research is needed, however, to better understand the processes and facilitative factors involved in the development of empowerment and engagement in advocacy for diverse families of children with ASD.

Calls for Research

Barriers to the identification, diagnosis, and access to services can have an effect on the quality of life for family members of children with ASD, as well an effect on long-term education, intervention, and public health costs (McMorris, Cox, Hudson, & Liu, 2013). As such, research aiming to better understand and reduce the barriers for families with children with ASD could lead to more positive outcomes. Families need more effective ways to learn about their children’s disabilities, symptoms, and relative strengths, as well as better methods for deciding between and receiving multiculturally-competent, family-centered services and treatments (Lord & Bishop, 2010). Understanding families’ experiences may be critical to improving the diagnostic process (McMorris et al., 2013). Parents’ beliefs and interpretations of the symptoms and etiology combined with their experiences with the health care system may influence treatment decisions, setting the stage for how parents proceed with treatment options for their child and develop relationships with professionals (Lavelle et al., 2014; Moh & Magiati, 2012).

Thus, examining diagnostic and service utilization experiences may yield valuable information for improving diagnostic practices and the service delivery system for families of children with ASD. With this information, professionals can minimize barriers to diagnosis, provide parents with the most appropriate guidance and, working together, they can make the best possible decisions regarding the child's overall development. On a larger scale, findings may help professionals and policy makers to work towards supporting equitable diagnostic pathways for parents and children in underrepresented sociodemographic groups.

Given the challenges faced by parents of children with ASD, and the likelihood that even systemic improvements will not eliminate all of these barriers, facilitating family empowerment and advocacy skills for caregivers may also contribute to better outcomes. Fisher (2008) suggests that while the parents of children with disabilities often work to feel more empowered within their personal microsystems, this is not always facilitated by their encounters with health and social care organizations, especially when children are attributed 'deficient' identities in ways that may undermine empowerment. Services that seek to empower must value diversity without placing the burden entirely onto the individual (Fisher, 2008). Additionally, as service providers attempt to become more family-centered in their approach, establishing their role as facilitators of family empowerment and advocacy becomes increasingly relevant (Nachshen, 2005).

At present, there are limitations and gaps within the existing body of literature pertaining to empowerment in families of children with ASD. As Nachshen and Minnes (2005) highlight, less well-educated, poor families with children with ASD have not been well-represented in the existing literature on empowerment. This is an important

limitation to address because families with low SES may experience empowerment differently (Nachshen & Minnes, 2005). The present study addresses the gaps in the literature by utilizing a transformative phenomenological design to explore the experiences of low-SES and ethnic minority families as they underwent the diagnostic and service utilization processes. The utilization of a transformative design also allows for an explicit focus on social justice and advocacy within the study, such that the research questions guiding the study focus on participants' experiences of empowerment and advocacy within the diagnostic and service utilization processes. Findings may shed light on ways to minimize barriers to services and early diagnosis for these underserved groups. Findings may also inform service providers seeking to facilitate family empowerment and engage in empowering relationships with parents of children with ASD, as well as policy makers seeking to improve diagnostic and service delivery pathways.

Conceptual Framework

The conceptual framework guiding the study draws from the existing literature examining families' experiences of obtaining a diagnosis and accessing and utilizing services for their child with ASD within Bronfenbrenner's ecological model (Bronfenbrenner, 1989) and a social justice perspective. This conceptual framework consists of major themes that make up families' experiences going through the diagnostic and service utilization process for their child with ASD, including facilitators and barriers for this process. This conceptual framework was suspended to the best of my ability during the data collection phase and was reintroduced during the analysis and synthesis

stages to serve as a lens for integrating, interpreting, and describing the data (Giorgi, 2009).

Diagnostic and service utilization experience. According to the existing literature, parents' experiences can be grouped into major themes, including initial recognition that their child was developing atypically; waiting, worry, and uncertainty; preference for diagnostic information and treatment decisions in a hopeful, family-centered, and collaborative way; feeling overwhelmed with information and emotion at diagnosis and when treatment planning; processes of grief, relief, and making sense of ASD; and difficulty navigating the health care and service delivery systems. The associated psychological experiences of some of these processes include experiencing a discouraging assessment and diagnostic process that results in parents feeling frustrated, confused, stressed, disempowered, and overwhelmed.

Barriers. On a family level, barriers to obtaining an early diagnosis and accessing and utilizing services include child symptom severity, belonging to a racial or ethnic minority group, living in a nonmetropolitan area, having limited education, and belonging to low SES group. On a broader systemic level, barriers include pediatrician feedback to "wait and see," long wait times throughout the process, high out-of-pocket costs, dissatisfaction with treatment options and availability, and difficulty finding appropriate support, respite, and childcare services.

Facilitators. Higher levels of parent resourcefulness and ability to actively seek treatments and interventions for their child (advocacy), family empowerment, and empowering parent-professional relationships are associated with more positive experiences for families as well as more effective service delivery.

Purpose of the Study

The purpose of this integrated phenomenological research project is to acquire knowledge of parents' psychological experiences obtaining a diagnosis and accessing services for their child with ASD by examining the actual situation, as lived through and experienced by the parents themselves. In addition, I was also interested in gaining knowledge of the meaning and function of advocacy and empowerment for the parents going through these experiences. Lastly, I was interested in utilizing the acquired knowledge to draw implications for mental health professionals, service providers, and policy-makers. In order to understand the phenomenon under investigation using a transformative phenomenological design I utilize phenomenon-related research questions and procedural questions to guide the analysis and synthesis procedures. Procedural questions are highlighted in Chapter III. The following phenomenon-related research questions are listed below:

Central Question:

- What is the lived psychological meaning of parents' experiences going through the diagnostic and service utilization process for their child with ASD?

Issue Subquestions:

- What is the psychological meaning of empowerment for parents' experiences going through the diagnostic and service utilization process for their child with ASD?

- What is the psychological meaning of advocacy for parents' experiences going through the diagnostic and service utilization process for their child with ASD?

Additional Question:

- What recommendations do interviewed parents have regarding the diagnostic and service utilization processes for other parents, service providers, and policy-makers?

CHAPTER III

METHODS

This chapter describes the study research methodology and the following areas: (a) rationale for research approach, (b) description of research sample, (c) summary of information needed, (d) overview of research design, (e) methods and data collection, (f) plan for analysis and synthesis of data, (g) ethical considerations, (h) issues of trustworthiness, and (i) limitations of the study. The chapter culminates with a brief concluding summary.

Rationale for an Integrated Research Design

“Qualitative research” is a broad term including such varied methods and methodologies that it is not helpful in describing this study. As such, the specific term “phenomenological qualitative research” will be used. Phenomenology is grounded in a constructivist philosophical paradigm. It is concerned with how the complexities of the sociocultural world are experienced, interpreted, and understood in a particular context at a particular point in time (Bloomberg & Volpe, 2008; Merriam, 1998). The intent of phenomenological research typically is to examine an event, situation, or interaction by allowing a researcher to enter the world of others in an attempt to achieve a holistic rather than a reductionist understanding (Bloomberg & Volpe, 2008; Merriam, 1998). Phenomenological research tends to emphasize discovery and description, and the objectives are generally focused on extracting, describing, and interpreting the meaning of experience (Bloomberg & Volpe, 2008; Merriam, 1998).

It is my contention that purely quantitative methods are unlikely to elicit the rich data necessary to address the proposed research questions. Because this study attends to

aspects of experience that are not easily operationalizable, they are best captured using an integration of complementary methods, also known as mixed-methods. The demographic information helped me engage in purposeful sampling for an in-depth phenomenological interview with parents from underprivileged groups, specifically, parents from ethnic minority groups and parents from low SES backgrounds. By including the preliminary quantitative analysis, I was able to examine the experiences of the larger sample as captured by quantitative measures of empowerment and satisfaction with services. To rely solely on the quantitative empowerment and satisfaction measures to attempt to understand parents' psychological experiences would constraint the data, however. Instead, this data served as a point of departure for the phenomenological interviews. Hanson et al. (2005) argues that quantitative and qualitative methods can be combined to use results from one method to elaborate on results from the other method (complementarity). Yanchar and Williams (2006) support this argument for an integration of methods in their soft incompatibility thesis, which states that even though methods may be situated within their own philosophical context, researchers and theorists could be allowed to form a coherent strategy/methodology that could be adapted to questions and problems as they arise over the course of inquiry. In order to accomplish this, Yanchar and Williams (2006) state that researchers should acknowledge that methods are inextricable from underlying assumptions, and should identify underlying values, assumptions, and theoretical commitments of the methods utilized.

Rationale and Overview: Descriptive Phenomenological Methodology

Of the various integrated approaches available, this study was most suited for an unbalanced, sequential, transformative integrated design depicted as [quan → QUAL]

and situated within a descriptive phenomenological study (Giorgi, 2009; Hanson, et al., 2005). An integrated, or mixed-methods, study is unbalanced when one methodology is given priority over the other. The term sequential refers to the fact that the methods are carried out sequentially, as opposed to concurrently. The term transformative refers to a study that is being carried out with an explicit social justice lens. The depiction [quan → QUAL] illustrates the unequal sequential design, with quantitative methods being carried out first, but with qualitative phenomenological methods being given priority.

Within the phenomenological framework, Giorgi (2009) argues that phenomenology is neutral with respect to research strategies, so long as the methods chosen match the purpose and research questions. Giorgi defines phenomenology as a sufficiently comprehensive perspective to be the basis for a complete philosophy of science, with the ability to justify quantitative, qualitative, and even integrated approaches. Despite being one of the most methodical and systematic phenomenological approaches, Giorgi's descriptive phenomenology needs to also be flexible, in the sense that the steps are implemented in a manner sensitive to the research situation and data.

Phenomenology is a philosophical tradition generally understood to have been founded by Edmund Husserl (1913/1983) at the beginning of the 20th century that focuses on the activities of consciousness and the objects that present themselves to consciousness (intentionality; Giorgi, 2012). Phenomenology views objectivity as something which appears within intentional consciousness; objectivity is discovered within the lived world. Within a phenomenological framework, research takes place in the lifeworld—*Lebenswelt*- which Finaly (2012) defines as the matrix of meanings inherent in our ongoing relations with our world. Furthermore, the lifeworld:

points to our embodied sense of self, which is always in relation to others given through shared language, discourse, culture, and history. We have a sense of time, living in an unfolding present with a determining past and yet-to-be determined future; we are thrown into spatial relationship in the world surrounded by things that have meaning while we engage activities that become our projects. We share lifeworlds with others while also having our own unique vantage point (p. 180).

The goal of phenomenological research is to describe the lived experience of the participants and the meaning of that experience from the participants' perspective (Creswell, 1998). Phenomenology is grounded in the assumption that ultimately the only reality we have on which to base claims is the reality that we experience from a first person perspective (Merleau-Ponty, 1962). The present study drew from the descriptive phenomenological method as outlined by the humanist psychologist Amedeo Giorgi (2009, 2012). Giorgi's method is founded on the assertion that "psychology, as a human science, requires a praxis that offers an alternative to the empirical while equaling the empirical in its clarity of articulation, epistemology, and guidance for practitioners. He builds upon the work of Husserl and Merleau-Ponty in his effort to articulate an alternative, humanistic epistemology to guide psychology as a human science" (Applebaum, 2012, p. 46). Thus, Giorgi's descriptive phenomenological method is a means to illuminate the psychological meanings already present in participants' lived experiences of the world. Through this process, a researcher attempts to explicate and understand psychological meanings that are claimed to be present but only implicitly so. As such, Giorgi describes his method as descriptive. In a larger sense, of course, the psychological analyses performed in Giorgi's descriptive phenomenology are

interpretations in so much as they are psychological interpretations of life-world events that are broader than the psychological understandings researchers bring to them. These analyses are done by means of a descriptive method (Giorgi, 2012). Despite being called descriptive phenomenology, this does not rule out phases where interpretations also take place. Interpretation may be used, and may be called for, in order to contextually understand parents' psychological experiences, as long as it remains descriptively grounded (Wertz, 2005).

Descriptive phenomenology is not ideologically driven. This decomplicates the process of integrating methodologies because there is no need to resolve conflicting ideologies. Instead, phenomenological methods can be subsumed within the ideology guiding the research questions and goals. Furthermore, because the phenomenological process requires researchers to attempt to enter and openly respect individuals' own points of view, and honor the multiple perspectives found in the lifeworld (Wertz, 2005), it does lend itself well to be incorporated within transformative and social justice-oriented methodologies. In the present study, phenomenology is a fitting methodology to provide culturally critical and emancipatory knowledge regarding the phenomenon under investigation.

In order to adequately understand and transform macrosocial influences, researchers must first understand the psychological experiences of individuals that are enlisted, sustained, and/or trapped in those dynamics (Wertz, 2005). In the context of this study, I wished to understand the experiences of parents as they face multiple aversive systemic barriers in their efforts to obtain a diagnosis and appropriate treatment for their child. In humanizing human life and humanizing human institutions through research and

the resulting text, individuals that partake in the research and dialogue with the text may become increasingly thoughtful and better prepared to act tactfully in future situations (van Manen, 1990). It is my hope that when individuals can engage reflectively with a humanizing text examining participants' experiences, there exists an opportunity for personal transformation and, on a larger scale, social transformation. As such, the descriptive phenomenology used in the present study seeks to examine reality as it presents itself through individual consciousness. In order to do so, the unit of analysis is individual experience, collected through interviews between myself and the participants. In regards to axiology, because phenomenological methods are inherently reflective, I openly acknowledge the values that shape the narrative being presented, including the participants' values as well my own (Creswell, 2003). The method of analysis is primarily descriptive and the mode of representation is third person descriptive prose.

Research Sample

A purposeful sampling procedure was used to select this study's sample. To yield the most information about the phenomenon under study, purposeful sampling is a procedure that is typical of phenomenological methodology (Wertz, 2005). As highlighted in the literature, parents belonging to oppressed and underrepresented groups face significant challenges in obtaining a diagnosis and accessing services for their child with ASD. Purposeful sampling allows selection of participants belonging to oppressed or underrepresented groups, such as racial and ethnic minorities and those with low SES. Participants were selected from the Wave II sample of participants in the Oregon Early Autism project (Early Autism Project; PI, McIntyre; see also McIntyre & Barton, 2010). The criteria for selection of participants was:

- Participants have a child diagnosed with ASD, or a pre DSMV-TR equivalent (autistic disorder, PDD-NOS, Asperger's syndrome, autistic disorder)
- Participants were currently residing in the Pacific Northwest
- Participants completed both Wave I and II of the Oregon Early Autism Project
- Participant were of low SES, relative to the larger sample

The nature and number of participants cannot be mechanically determined beforehand or by formula in phenomenological research, however, deliberation and critical reflection considering the research problem, the life-world position of the participants, the quality of the data, and the value of emergent findings with regard to research goals may yield an estimate. For this study, the research sample for the quantitative analysis includes all participants that completed Wave II of the Oregon Early Autism Project ($n = 31$). For the phenomenological interviews, the sample included six participants, which was enough to achieve saturation, that is, redundancy of findings that fulfill the research goals (Englander, 2012; Wertz, 2005).

Research Design Overview

The following steps were used to carry out this sequential transformative integrated [quant → QUAL] research. Following this list is a more in-depth discussion of each of these steps.

1. I secured IRB approval for this study.
2. I obtained the Wave II data set with sociodemographic variables and conducted a descriptive exploratory analysis of the quantitative data. This analysis of the

- larger sample explored sociodemographic features of the sample, participants' responses on scales measuring family empowerment and parental advocacy, parents' responses on scales measuring satisfaction with services, and correlations among sociodemographic variables and the measures of empowerment and advocacy.
3. I engaged in purposeful sampling for the phenomenological interview after Wave II data collection was complete by selecting participants with the lowest family incomes. Potential participants were contacted by telephone by an OEAP staff member inviting them to participate in the phenomenological interview. I contacted those who agreed to participate in order to schedule them for the first interview.
 4. I conducted two individual semi-structured, in-person, in-depth interviews with each of the selected participants from the larger sample. Interviews were recorded and took place in the participants' homes or at another specified location preferred by the participants.
 5. I analyzed the phenomenological qualitative data according to the descriptive phenomenological methods described by Giorgi (2009, 2012), with integration of the quantitative and phenomenological qualitative data occurring during the data synthesis stage. In order to guide the phenomenological analysis, the following procedural subquestions were addressed:
 - What statements describe these experiences?
 - What are the “meaning units” units in the text, given a psychologically sensitive interest in the phenomenon under investigation?

- What do the meaning units reveal about the phenomenon under investigation?
- What do the “meaning units” reveal about the psychological structure of these experiences?
- What implications do the psychological structure of these experiences have for parents of children with ASD, service providers, and policy-makers?

Data-Collection Methods

The use of multiple methods is critical in attempting to obtain an in-depth understanding of the phenomenon under study. This strategy adds rigor, breadth, and depth to the study and provides corroborative evidence of the data obtained (Creswell, 1998). Therefore, this study utilized an integrated approach that includes both quantitative data from structured interviews as well as in-depth phenomenological qualitative data from semi-structured interviews.

Structured interviews. Potential participants were contacted as a part of Wave II Oregon Early Autism data collection (Early Autism Project; PI, McIntyre; see also McIntyre & Barton, 2010). Those who agreed to participate were scheduled for an at-home interview with a team of two trained interviewers. Data was collected orally during structured interviews, with the exception of items sensitive in nature (e.g. family income). Structured interviews can be easy to administer, code, and analyze, but can be of limited value for examining complex social relationships or intricate patterns of interaction (Bloomberg & Volpe, 2008). For the purposes of the present study, structured interviews collecting primarily quantitative data have a distinct place in the study’s methodological design and served as a useful complement to other data-collection methods.

Measures. I utilized three measures included in the full structured interview

protocol being used for Wave II of the Oregon Early Autism Project: the sociodemographic survey, the parental satisfaction with services scale question, and the Family Empowerment Scale (FES; see Appendix A).

Sociodemographic Survey. The sociodemographic variables of interest include the SES-indicator items years of education (write in response), level of completed formal education (10 response options), number of persons in the home (write in response), perceived financial strain (four response options), and annual family income (13 response options). Participants also reported race/ethnicity with six response options and the option to select more than one and write in their own. These variables were selected from the existing data set to provide contextual information regarding the larger sample. Items and options are presented in Appendix A on p. 116.

Parental Satisfaction. Respondents were asked to self-report their level of satisfaction with their child's current services with a single satisfaction item. Satisfaction was reported on a 5-point scale (1 = *very unsatisfied*, 3 = *neutral*, 5 = *very satisfied*).

Family Empowerment Scale (FES; Koren et al., 1992). The FES is a 34 item parent-report measure that assesses current empowerment as it relates to parenting a child with disabilities in terms of (a) Attitudes, what a parent feels and believes; (b) Knowledge, what a parent knows and can potentially do; and (c) Behaviors, what a parent actually does. The FES includes three sub-scales, all of which were used in the present study: (a) Family, that is, the immediate situation at home and the parent's current management of day-to-day situations (12 items; sample item "When problems arise with my child, I handle them pretty well"); (b) Service System, or the professionals and agencies that provide services to the parent's child (12 items, sample item "I know the

steps to take when I am concerned my child is receiving poor services”); and (c) Community/Political, that is, legislative bodies, policy makers, agencies, and community members who are concerned with or who influence services for children with intellectual and developmental disabilities and their families (10 items, sample item “I feel I can have a part in improving services for children in my community”). This final subscale primarily involves the parent's advocacy for improved services for children in general, rather than specifically for their own child. Responses are indicated on a five-point Likert-type scale ranging from ‘very untrue’ (1) to ‘very true’ (5), with higher scores representing more empowerment. Total scores are derived by summing subscale items, with ranges of 12-60 on the Family and Service System subscales and 10-50 on the Community/Political subscale. According to Koren et al. (1992), the scale was found to have adequate internal consistency for each of the three subscales (Family: $\alpha = .88$; Service System: $\alpha = .87$; and Community/Political: $\alpha = .88$). The four week test- retest reliability ($N = 107$) was also found to be adequate for each of the three subscales (Family: $r = .83$; Service System: $r = .77$; and Community/Political: $r = .85$). Validity of the scale was assessed through a factor analysis, which provided support for the correspondence of items to the Level Dimension (Family, Service System, and Community/Political) of the conceptual framework. The questionnaire was also found to significantly discriminate between parents who were involved in a variety of advocacy-related activities and those who were not (Koren et al., 1992).

Semi-structured interviews. The semi-structured phenomenological interview was selected as the primary method for data collection in this research. The individual, in-depth interview method was of most use to this study because it had the benefit of

offering the potential to capture a person's perspective of an event or experience in order to best understand the person's psychological experiences (Creswell, 1994). Further, it offered the opportunity to clarify statements and ask for additional information. Wertz (2005) describes interviews as especially useful "when the phenomenon of interest is complex in structure, extensive in scope, and/or subtle in features that participants are not likely to offer spontaneously in response to questions or instructions at the outset" (p. 171), as is the case with the phenomenon under investigation in the present study.

Although phenomenological interviews have clear strengths, there are limitations associated with interviewing (Giorgi, 2009). First, not all people are equally cooperative, articulate, and perceptive. Another consideration is that retrospective accounts, which will be used in this study, may be unreliable or distorted from an objective view of reality or events (Giorgi, 2009). Furthermore, interviews require researcher skill to elicit richly detailed descriptions of psychological experiences. Lastly, interviews are not neutral data-collection tools. They are the product of an interaction between interviewer and interviewee and the context in which they take place (Fontana & Frey, 2003; Rubin & Rubin, 2005; Schwandt, 1997). The phenomenological stance then, according to Giorgi (1997), is to acknowledge the role of consciousness and context and take it into account rather than ignore it; this stance is a rigorous and necessary component of carrying out this methodology.

Phenomenological qualitative interview schedule. Key indicators identified in the psychology, social work, and ASD literature, along with the research questions guiding this study were utilized as a framework to develop the qualitative interview questions. The additional recommendations question was included as deliberate strategy

to elicit parental knowledge for the benefit of others, and as a way of supporting parent empowerment and acknowledging their strengths through the design of the study.

Phenomenological qualitative interview process. Following IRB approval (see Appendix B), selected participants from the Wave II sample were contacted via telephone by a staff member of OEAP using their contact information that was provided during the OEAP interview to request permission for the PI to have access to their contact info and for her to contact them about participation in the present study. I then contacted those that agreed in order to provide an overview of the project and activities using the Phone Recruitment and Scheduling Script (see Appendix C). If the parent agreed to participate, they were scheduled for the first of two 90-minute interviews. All participants contacted agreed to participate.

All interviews took place between July 22, 2015 and October 2, 2015 and ranged from 30 to 90 minutes in length. Before the first interview began, the interviewee was asked to review and sign a university consent form required for participation in this study (see Appendix C and D). Follow-up interviews were scheduled to clarify participant responses and/or dive deeper into a particular response. All interviews were audio-recorded and transcribed verbatim. In addition, the interviewer kept detailed field notes documenting the interview setting and non-verbal communications. Families received \$40 for their time upon completion of the second interview. The compensation was provided to all families, regardless of whether they completed the two interviews (and all questions). All participants included in the qualitative interview portion of this study completed both interviews. Lastly, a brief, three-page summary of initial findings was

mailed to all participants interviewed and participants were informed that feedback and requested revisions were welcomed (see Appendix E).

Methods for Data Analysis and Synthesis

In order to understand the phenomenon under investigation using a transformative phenomenological design, the following phenomenon-related research questions were used:

Central Question:

- What is the lived psychological meaning of parents' experiences going through the diagnostic and service utilization process for their child with ASD?

Issue Subquestions:

- What is the psychological meaning of empowerment for parents' experiences going through the diagnostic and service utilization process for their child with ASD?
- What is the psychological meaning of advocacy for parents' experiences going through the diagnostic and service utilization process for their child with ASD?

Additional Question:

- What recommendations do interviewed parents have regarding the diagnostic and service utilization processes for other parents, service providers, and policy-makers?

Quantitative data analysis. The quantitative data collected was not intended to test hypotheses, but to make sense of the contextual understandings of the phenomena under investigation. Using SPSS Version 21.0 (IBM Corp, 2012), demographic continuous variables were created for the Wave II sample in regards to caregiver age at time of Wave II interview, child age at time of Wave II interview, child age of ASD diagnosis, maternal education in years (all participants were mothers of the child with ASD), and approximate family income. Additionally, I coded demographic categorical variables for caregiver race/ethnicity, educational attainment, relationship status, approximate family income in regards to poverty thresholds, and perceived financial strain. I calculated the family income variable by comparing self-reported income to the 2015 federal poverty thresholds (Federal Poverty Level, 2015) and recoded family income into a dichotomous categorical variable identifying whether a family was within 150% of the federal poverty line or above. I then calculated means and standard deviations for each of the three subscales of the FES measure as well for satisfactions ratings for current services (rating scale of 1-5). These processes were then repeated for the subsample of six participants included in the follow up qualitative interviews.

Cronbach's alphas for the 12 Family items, 12 Service System items, and 10 Community/Political items were .79, .77, and .81, respectively, in the full sample. Pearson product-moment correlation coefficients were computed to explore relationships between sociodemographic continuous variables (maternal education, approximate family income) and subscale scores of FES and satisfaction with current services in the whole Wave II sample.

Phenomenological qualitative data analysis. Once the phenomenological qualitative interviews were conducted and their contents recorded and transcribed, the first step in the descriptive phenomenological analysis, as outlined by Giorgi (2009, 2012), was to assume the attitude of the scientific phenomenological reduction, otherwise known as the eidetic reduction. The scientific phenomenological reduction is a methodological device based on Husserl's work in order to help make research findings more precise. In order to complete this step, I (a) bracketed past knowledge about the phenomenon under investigation, in other words, suspended previous knowledge and potential biases, in order to encounter it freshly and describe it precisely as it was experienced, and (b) considered what was given precisely as it was given, that is, to understand the phenomenon under investigation precisely as it was described by the participants, without added interpretation (Giorgi, 1997). Additionally, I reflected not only on what was experienced, but also on the psychological processes that were involved and in this way carried out an intentional analysis using the phenomenological psychological reduction (Wertz, 2005). This means that in addition to attending to what was heard, I also attempted to understand intangible elements of the communication via non-linguistic cues (e.g. bodily, perceptual, emotional, imaginative, social, behavioral) through reflection, field notes, and journaling. Once the attitude of the scientific phenomenological reduction was assumed, following procedural questions guided the analyses:

- What statements describe these experiences?
- What are the “meaning units” units in the text, given a psychologically sensitive interest in the phenomenon under investigation?

- What do the meaning units reveal about the phenomenon under investigation?
- What do the “meaning units” reveal about the psychological structure of these experiences?
- What implications do the psychological structure of these experiences have for parents of children with ASD, service providers, and policy-makers?

The interview transcripts were imported into a qualitative data analysis software program called *Dedoose*, which was the primary tool for analyzing data. Each participant’s two interview transcriptions were read in their entirety while simultaneously listening to the audio recordings in order to get a sense of the whole. This phenomenological approach is holistic, and so no further steps were taken until an understanding of what the data were like was achieved for each participant.

The next step involved going back to the beginning of the description (the participant’s qualitative data) and beginning to reread it, marking shifts in meaning in order to break up the data into its constituting parts. Giorgi (2012) refers to these parts as meaning units, and explains they are arbitrary and carry no theoretical weight. The meaning units are meant to be determined by the psychological criteria guiding the study as well as the researcher’s attitudes. By the end of this step, there was a series of meaning units in the transcriptions, transformed, or coded, into expressions that were more indicative of the psychological experiences from what the participants said. Put simply, this process involved applying descriptive codes to sections of text that seemed to hang together in describing psychologically relevant aspects of the participants’ experiences (e.g. Empowerment, Advocacy, Fear of future, Social pressure/stigma).

Freely changes aspects or parts of a phenomenon or object, and [the researcher] sees if the phenomenon remains identifiable with the part changed or not.

Ultimately, the use of the method depends upon the ability of the researcher to awaken possibilities. Whatever is given factually becomes one example of a possible instance of the phenomenon, and by multiplying possibilities one becomes aware of those features that cannot be removed and thus what is essential for the object to be given to consciousness (p. 6).

With the help of free imaginative variation, data was reduced to what I found to be the essential components, or constituent parts, that comprised a general structure of the participants' shared experience undergoing the diagnostic and service utilization processes. Although all the data were analyzed and reviewed, it should be noted that I was not interested equally in all the data, but rather, I was especially sensitive to the meaning units where psychological richness exists. Giorgi (2009) explains, "This method demands that this step be something 'lived' rather than intellectualized. From the psychological attitude, one follows one's felt sensitivity to direct one to the aspects of the meaning units that seem to be especially revealing in a psychological sense" (p. 182). Each meaning unit was interrogated for the insight and implications that it had for the psychological experience of the phenomenon under investigation. Through the process of transforming the data, often multiple times, the revealing meaning units stand out against all the other meaning units. For example, in regards to experiences of the diagnostic process, meaning units revealing feelings of uncertainty about what ASD means were favored over meaning units revealing neutral feelings about having their child be observed during the diagnostic process. The former was included in the results, while the

latter was not. These decisions were made by maintaining the attitude of the psychological reduction, keeping the research questions in mind, interrogating each meaning unit for its relevance and implications on the psychological experiences of the phenomenon, and attending to frequency and psychological richness of each meaning unit. In this manner, the data were reduced to the essential constituents comprising the general structures.

Rather than being stand-alone themes, constituents are defined as inter-related parts of the whole general structure, in which each part must be present for the whole structure to be maintained. A structure usually consists of several key constituent meanings as well as the relationship among the meanings. A key test of a structure is to see if the structure “collapses” if any of the constituents is removed, indicating a faithful accounting and integration of the various descriptions has been achieved (Giorgi, 2009). The constituents that make up the general structure must capture each participant’s experience without forcing a shared experience from the data, and must relate to each of the other constituent parts. In this manner, an essential structure of this shared experience was written from a psychological perspective, that is, with a focus on participants’ cognitive and emotional responses and experiences.

Additionally, the role of critical self-reflection in the present study was continuously and explicitly acknowledged. A two-fold process of increasing awareness of power dynamics and critical self-reflection is necessary to reflect on both prior and evolving understandings during the research processes (Finlay, 2008; McWhirter, 1997). Finlay (2008) argues that in order for researchers to effectively bracket out prior knowledge and assumptions during the phenomenological reduction, they must first

possess an awareness of what it is they are striving to bracket out; critical self-awareness (i.e., reflexivity) is necessary. The phenomenological attitude is a reductive-reflexive dance in which “the researcher slides between striving for reductive focus and reflexive self-awareness; between bracketing pre-understandings and exploiting them as a source of insight” (Finlay, 2008, p. 1). As such, detailed notes were kept, reflecting on both the content and process of each step of the analysis. Notes were also taken to record the process and content of the regular meetings with the Devil’s Advocate (see section on limitations) for this study.

Ethical Considerations

In any research study, ethical issues relating to the protection of participants must be of vital concern (Merriam, 1998). A social science researcher is responsible for both informing and protecting study participants, and as such, needs to take steps to safeguard against potential ethical threats. In order to do this, participation in the study was voluntary and in no way impacted participation in the larger study, participants were informed about the study’s purpose, written and oral informed consent was collected from each participant, and names and/or other identifying information was kept confidential. Cautionary measures were taken to secure the storage of research-related records and data, and nobody other than myself and select members of my committee had access to this material.

Validity and Reliability

In phenomenological research, validation refers to an attempt to assess the accuracy of findings, as best described by the study participants and myself (Creswell, 2013). Validity is a strength of phenomenological research in that the final descriptive

account comes from extensive time in the field during data collection (I have been interviewing participants from this sample since Wave I data collection in 2011), a detailed thick description of participants' experiences, and a closeness between myself and the participants in the study. All of these elements add to the accuracy of the study (Creswell, 2013).

In order to increase validity of the present study, triangulation, the process of corroborating data from different sources or methods to shed light on themes (Creswell, 2013; Glesne & Peshkin, 1992; Lincoln & Guba, 1985), was utilized. Data from the phenomenological interviews was compared with data from Wave II, including responses to scale questions assessing parents' satisfaction with the diagnostic process and responses on the FES. Peer debriefing sessions (Creswell, 2013; Glesne & Peshkin, 1992; Lincoln & Guba, 1985) was also utilized, in which a peer and colleague served as the Devil's Advocate to continuously question motives, methods, biases, and conclusions. For example, the Devil's Advocate, upon hearing my initial codes, asked why I chose those particular terms and questioned why I conceptualized certain excerpts as "empowerment" and/or "advocacy." In addition, a process of member checking (Creswell, 2013; Glesne & Peshkin, 1992; Lincoln & Guba, 1985) was utilized, in which a brief, three page summary of the structural description of the phenomenon under study was given to the participants interested in reading it in order to check its accuracy. Participants were encouraged to provide feedback within two weeks of receiving the summary if they had any requested revisions to allow for incorporation of their revisions into the final document (no participants provided feedback). Lastly, the thick description of the phenomenon allows readers to make decisions regarding transferability (Creswell,

2013; Lincoln & Guba, Merriam, 1988); readers are able to make decisions regarding which themes and details may transfer to other settings.

In quantitative research, reliability refers to whether the findings are consistent and dependable with the data collected (Lincoln & Guba, 1985). The goal is not to eliminate inconsistencies, but to ensure there is an understanding of when they occur (Bloomberg & Volpe, 2008). In the present study, the issue of reliability was addressed through detailed field notes, quality audio recording, transcriptions indicating pauses and overlaps, and detailed records of procedures demonstrating consistent implementation.

Chapter Summary

In summary, this chapter provided a detailed description of the methodology for this study. A phenomenological unbalanced sequential transformative design was employed to examine the phenomenon of going through the diagnosis and service utilization process for a child with ASD. The participant sample for the quantitative analysis included all participants that have completed Wave II of the Oregon Early Autism project, and the participant sample for the phenomenological interviews included six participants purposefully selected from the Wave II sample. The data was analyzed and synthesized according to the guidelines for a descriptive phenomenological analysis as outlined by Giorgi (1997, 2009, 2012). Validity and reliability was accounted for through various strategies, including method triangulation, thick description, peer debriefing, and member checking.

CHAPTER IV

RESULTS

In this chapter, the results of the analyses are presented for the central research question, issue subquestions, and additional recommendations question. First, I describe the results of the descriptive quantitative analysis for both the Wave II sample and the subsample of participants included in the follow-up interviews with regards to sociodemographic variables, Family Empowerment Scale scores, and parent satisfaction ratings for current services for their child. This description is included to triangulate data collected for the phenomena under investigation by examining the sociodemographic descriptors and experiences with empowerment and service utilization as initially captured by quantitative measures. Then, the results from the qualitative phenomenological reduction are described in regards to the central research question, issue subquestions, and additional recommendations question. The constituent parts that make up the general structure, or collective experience, corresponding to each research question are then discussed in order to provide a deeper understanding of the participants' experiences. Throughout the chapter, participants are quoted to illustrate the lived meaning of their experiences, and to provide a platform for their voices to be heard and their experiences to be honored.

Descriptive Quantitative Analysis

Demographic variables. Demographic and descriptive data for the full sample ($N = 31$) and the subsample of interviewed participants ($n = 6$) is presented in Tables 1 and 2. In all six cases, respondents were female primary caregivers of the target child with ASD.

Table 1

Family Demographic Categorical Variables

Variable	Wave II Sample ($N = 31$)		Subsample ($n = 6$)	
	<i>n</i>	%	<i>n</i>	%
Race/Ethnicity				
White/Caucasian	26	83.6	3	50.0
Hispanic/Latino	6	19.4	3	50.0
Maternal education				
High school/GED	6	19.4	2	33.3
Partial college (≥ 1 year)	6	19.4	0	0.0
Specialized training	2	6.5	1	16.7
Junior college	7	22.6	1	16.7
Standard college	6	19.4	2	33.3
Graduate degree	4	12.9	0	0.0
Relationship status				
Single	6	19.4	1	16.7
Domestic partner	25	80.6	5	83.3
Approximate family income				
150% of poverty line or below	15	48.4	5	83.3
Above 150% of poverty line	16	51.6	1	16.7
Perceived financial strain				
Not enough to get by	3	9.7	2	33.3
Just enough to get by	15	48.4	4	66.7
Only worry for extras	12	38.7	0	0.0
Never worry about money	1	3.2	0	0.0

Table 2

Family Demographic Continuous Variables

Variable	Wave II Sample ($N = 31$)		Subsample ($n = 6$)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Caregiver age	41.0	8.1	39.2	7.9
Child age	8.0	1.5	8.7	1.1
Child age of diagnosis	1.7	0.7	2.2	0.4
Maternal education	15.1	2.3	14.2	2.4
Approx family income	50,403.2	29,728.6	32,500.0	9,219.5

Empowerment and satisfaction with services. Empowerment scores and satisfaction ratings for the full sample ($N = 31$) and the subsample of interviewed participants ($n = 6$) is presented in Table 3.

Table 3

Family Empowerment and Satisfaction with Current Services

Variable	Wave II Sample ($N=31$)		Subsample ($n = 6$)	
	<i>M</i>	<i>SD</i>	<i>M</i>	<i>SD</i>
Family empowerment scale				
Family	49.7	4.7	51.0	4.8
Service systems	51.6	4.9	50.7	5.6
Community/political	31.4	5.9	32.0	9.1
Satisfaction current services	3.7	1.1	3.7	0.8

Note. Family and Service systems empowerment subscales are scored from 12-60 and Community/political empowerment subscales are scored from 10-50.

Correlations. For the larger sample there were no significant correlations between any of the sociodemographic continuous variables (maternal education, approximate family income) and any of the FES subscale scores (Family, Service Systems, Community/Political). There were also no significant correlations between any of the sociodemographic continuous variables and ratings of parental satisfaction with services. This may be due to insufficient power given the small sample size of 31 participants for the Wave II data. See Table 4.

Phenomenological Qualitative Analysis

Central research question: What is the lived psychological meaning of parents' experiences going through the diagnostic and service utilization process for

Table 4

Correlations Among Demographic Variables and Parent Satisfaction Wave II (N = 31)

Variable	1	2	3	4	5	6
Sociodemographic variables	▪	▪	▪	▪	○	▪
1. Maternal education	--	▪	▪	▪	▪	▪
2. Approx family income	.48*	--	▪	▪	▪	▪
Family empowerment measures	▪	▪	▪	▪	▪	
3. Family	.03	.20	--	▪	▪	▪
4. Service systems	-.03	.11	.74*	--	▪	▪
5. Community/political	.23	.25	.48*	.71*	--	▪
Satisfaction measure	▪	▪	▪	▪	▪	▪
6. Current services	-.30	.09	.23	.17	.15	--

* $p < .05$.

their child with ASD? Data from all participants included in the phenomenological qualitative interviews, P₁, P₂, P₃, P₄, P₅, and P₆, were combined into one general structure reflecting their essential common features pertaining to the central research question. After describing the general structure of participants' collective experience, I list the constituent elements, followed by an in depth description of each element.

The general structure for the participants' collective experience, P, was as follows:

For the P experience of going through the diagnostic and service utilization process for their child with ASD, P struggled initially with uncertainty regarding what a diagnosis of ASD meant for their child and for their child's future functioning. Following a diagnosis, P initially felt they had more access to information regarding next steps and services for their child. P felt they had more information to help them learn more about

their child. As P began to navigate the service utilization process, P experienced some strained relationships and frustration with family and other members of their social support network that misunderstood ASD and provided unhelpful and/or unsolicited advice regarding parenting their child. P struggled with feeling judged negatively by others for their child's behavior. P also became aware of and frustrated with a lack of information regarding service options and how to access them as their child's needs changed. P began to feel some distrust in the systems involved in service access as well as in some service providers that were not perceived to be helpful or collaborative. As their child aged, P's sources of information regarding services shifted from primarily service providers to other parents of children with ASD. P became aware of the importance of collaborative, strengths-based service providers, as well as the importance of having a community of parents of children with special needs. P experienced appreciation for their sources of support and information. P became more active in networking and online research to ask for help, learn about available services, and learn about how to access them. P came to see themselves as the expert on their child and identified the need to be critical, discerning, and persistent in identifying helpful services and pursuing access to them. Lastly, P experienced a recurring fear regarding access and availability of services their child will need in the future, particularly after P's death.

The following constituents comprised the general structure:

1. Uncertainty regarding what a diagnosis of ASD means and what will happen next in regards to child functioning and services.
2. Increased access to services and information regarding ASD and available services following a diagnosis.

3. Relational strain and frustration with people in social support network that misunderstand ASD and/or judge parent for their child's ASD behavior.
4. Awareness of challenges, barriers, and limitations in the service access and utilization process, leading to frustration and some distrust in service systems and service providers.
5. A desire and/or appreciation for sources of support and information regarding services: collaborative, strengths-based service providers and communities of other parents of children with special needs.
6. Engagement in ongoing research and networking to learn about available services and pathways to utilization.
7. A need to be the expert on their child in order to communicate clearly with professionals regarding their child's unique needs and to determine which services are worth pursuing.
8. Fear regarding availability of future services and child's future after parents die.

Constituent 1, *uncertainty regarding what a diagnosis of ASD means and what will happen next in regards to child functioning and services*, is reflected in the data of P₁ and P₂, highlighting the variability in caregiver responses to the initial diagnosis and feelings of uncertainty. P₁ reported that, "As a parent you get this diagnosis and you feel really stuck like okay what should I do? Should I fix my child? Should I just work on these little things? Should I just ignore this all and hopefully he'll like grow out of it and mature and all that, or are we going to stick here and do nothing?" P₁ described feeling "stuck" in uncertainty and indecision regarding next steps following a diagnosis for her child. She also alluded to experiencing some denial regarding what having ASD means for her child. While P₁ was eventually able to move past these initial feelings of

confusion and being stuck, she illustrated the overwhelming and complex psychological reaction caregivers experience following their child's diagnosis of ASD. P₂ also described a feeling of uncertainty in making sense of ASD:

For me personally, you kind of just kick into, 'Okay we are going to figure this out,' and after a few days, it took us a while to just kind of let it sink in and then go, 'Okay but what does that mean? I don't know what this autism thing is and what does it mean to have this diagnosis of classic severe autism and what does that look like?' It looks so different on anyone. No one could really tell you what could happen.

Much like P₁'s experience, P₂'s experience highlights feeling uncertain about what ASD means for her child and what to expect. Her experience contrasts that of P₁, however, in her experience of shifting into a problem-solving mode as a response to the diagnosis.

Constituent 2, *increased access to services and information regarding ASD and available services following a diagnosis*, demonstrates a positive aspect of the diagnostic process, resulting in some feelings of relief and hope for parents. According to P₁, following the diagnosis of ASD, she received a flood of helpful information, adding "It was like it opened up this big book of like where we could go, what we should do, who we should hang out with, what we you know just all these things, so it was wonderful." P₅ also described this positive experience,

After we got the diagnosis we were, it was all great and we finally had our answer and then I think that's when services started kind of pouring in and helping us more... I think after the diagnosis it got easier so because you get more support and more services help so we got a lot more information, and it's been helpful.

P₁ and P₅ both describe having more access to information after receiving a diagnosis for their child, and in turn, feeling as though they were able to have some of their initial questions answered regarding ASD and next steps. P₂ described the psychological impact of having access to information and answers:

It made me feel like validated and knowing okay I was not crazy for thinking he needed something more than what we knew what to give. I was also it made me think, ‘Okay, there is someone who does have an answer that has some hope and has some strategies that we can know what to do.’

Constituent 3, *relational strain and frustration with people in social support network that misunderstand ASD and/or judge parent for their child’s ASD behavior*, manifested as strained relationships with spouses, mothers, and in-laws. P₆ described how lack of understanding of ASD contributed to strained family relationships:

[My child] just did not want to separate from me, which made things for me really difficult, which made my marriage really difficult, which caused a lot of problems in my marriage... That was really stressful because also his parents are much older and they are from a generation that doesn’t recognize or understand autism. They just, my ex-husband actually told me I was making it up because I wanted attention and I said, “Really I could think of a lot better things to do to get attention. I don’t really need to make up a disability for my child.”

Four of the six participants interviewed reported that the added stress of having a child with ASD contributed to divorce. P₅ described this experience:

Me and his biological father, we ended up divorcing just because it was just, there was just too much stress and that is the downside to it, is that I kind of overtook

the mother role instead, and it was all about [my child] and that's how it should have been to begin with...It wasn't like it was heartbreaking because it was going to happen, one way or another, because we were just drifting apart anyways. I think with the autism it just kind of came out a little bit more than we just, it was too much stress for him and me at the same, under the same roof so we divorced. While other caregivers, such as P₂, did not go through a divorce, the impact of having a child with ASD on a father, and the resulting impact on family relationships, was still a theme:

But as a dad I think it's so much harder to see your boy go through this and not understand it and wanting to know how to help and not know how to help. That feeling of helplessness can really hit a dad hard and it really hit my husband hard. I think for him maybe even more than me, even though I feel like it's been huge for me I think even more he's just had people being able to keep him up, encouraged, and hopeful. It could have looked really a lot different. It did for a while look a lot of different. It was very overwhelming and very frustrating to know, 'What am I doing? How do I deal with this?'

For some participants, the most strained family relationships were between themselves and their own parents. P₁ stated, "My mom wanted me to keep fixing him like, read this, and do this and he will be that child you want him to be and it's like, 'Mom I already know that he is that child. I don't need to fix him anymore.' I did try." Similar to P₆, generational differences in parenting styles and misunderstandings of ASD may be contributing factors to the strained relationships, leading to feelings of frustration and judgment. P₂ described her response to feeling judged, "It's like too much. I just

stopped talking to people, because it's just, if they are not going through it, they don't know. They cannot visualize or a lot of them just think it's bad parenting. No. It's not bad parenting." P₄ described the different responses to feeling judged by others:

When she was little, I don't think they could tell it was autism and so they would say really rude things. It does put you in a frame, depending on who you are, it will cause you to stay at home. Or you get a little bit like me, where you have this face on, when you're out in public like 'Just say something to me.' I have this attitude.

Constituent 4, *awareness of challenges, barriers, and limitations in the service access and utilization process, leading to frustration and some distrust in service systems and service providers*, was reflected throughout all the interviews. Despite the varied challenges, barriers, and limitations highlighted by each participant, their reactions and responses shared some similarities. P₅ described what she felt was one of her biggest challenges in accessing desired services:

I think the biggest [challenge] is the behavioral services. That has a waiting list more than a mile long, they are constantly, I mean we've been on the waiting list for about four or five years now and we try to get into behavioral services like right after they started opening up and there was new openings. We've been on the waiting list for that long and we have been unable successfully to get in.

She added that she worried about not having access to this service on a daily basis, and stated that she felt as though she is constantly "waiting for the phone to ring" to let her know she is finally off the waiting list. P₃'s responses also reflected difficult experiences waiting for services:

We had appointments set up and [the caseworker] was a no show three times, and I had the school nurse too because she wanted to be there...So, we were not taken seriously and I felt lied to. I felt like my time was wasted... you get offered services and then there is no funding. There is not enough funding. Then you get put on a waiting list.

P₃ described some distrust not only in some service providers, but also in the systems themselves. P₄'s responses also reflected an awareness of some of the systemic limitations affecting her ability to access services for her child:

I have learned that if you don't know what's out there, the people providing the service are not necessarily going to tell you. They are not doing it on purpose. I think they are overworked, they are overwhelmed... I think unfortunately you are not going to be told everything and sometimes you'll find out a year or two later that they provide something you didn't even know about. Those were the kind of bummers, like I could have been doing this a year or two ago. I think that it's just built in the system unfortunately.... I think I still have a little anger about stuff. I try not to be angry. But it comes out with the feeling of, 'Why is it so hard to do this?' It's very hard when you are already using a lot of your energy to figure out what your child needs, get that taken care of, the next thing. Then over here I still have to figure out how to talk to [service providers]. So, that can get frustrating.

P₆ also described some distrust in the systems involved in service access and utilization.

I discovered early on...that the system wasn't just broken. The system was designed for you to fail. The information is difficult to access. It's there, but again access is such a misnomer. If you are looking for it you can find it. If you are

diligent in looking for it you can find it. Are they going to offer it up to you? Probably not... The system is designed for people to give up. The system is designed to anticipate that people will be tired and that people will be overwhelmed and that at some point they will give up and stop accessing resources.

Constituent 5, *a desire and/or appreciation for sources of support and information regarding services: collaborative, strengths-based service providers and communities of other parents of children with special needs*, is reflected in P₁'s description of collaboratively working with her child's behavioral specialist:

It's like unlocking one puzzle piece at a time it's just helpful in so many ways too because we are learning together all three of us. It's not like she knows more than I and I know more than her it's like an actual team. It's supportive, it's genuine, it's I don't know it's just fabulous. Because I didn't I haven't ever had that yet.

While P₁ emphasized collaboration, P₂ emphasized her appreciation for working with a strengths-based pediatrician:

I just really appreciated that understanding and just the understanding and the patience and me answering questions and again trying to be that mama that wants to showcase what he can do and like all the good things and being able to ask the hard questions in a gentle way and help me understand this is hard, but it's going to help us know how to help your son. That was so good and so different than what we had experienced before.

Similarly, P₅ also discussed the impact of having a positive experience with her child's pediatrician:

As long as you have a great pediatrician that is willing to advocate for you and your child, then it's great. She is really good about pushing a lot of things to where the insurance can pay for a lot of it.... anything that he needs, his doctor pretty much just she pushes for it. She tells me that, "The insurance is going to deny, but I'll push him and they'll be able to get it through."

Another common theme was an expansion in sources of support and information from solely pediatricians to also include other parents of children with ASD and other DDs. P₁ expressed the impact of finding an online community of parents with children with ASD:

I got into a group of mamas that we formed this forum on Facebook with like over 300 and something parents...Now we can go into this Facebook forum and we can talk about doctors and restaurants and places that we can take our children and people don't stare as much and they are supportive and helpful. Just humble and generous, and like I don't know, it's different. It's definitely different like now than it was then, because then I felt like, 'Oh my gosh I could pull my hair out,' and now it's just like, 'Okay I got this we can do this.'

Constituent 6, *engagement in ongoing research and networking to learn about available services and pathways to utilization*, is reflected in the data of P₄ and P₂. P₄ shared her experience realizing the importance of conducting her own research in order to help discriminate between service options:

Well, I think I've learned you have to do some research on your own to understand because especially in the beginning. In the beginning you are very foggy and it's very hard to grasp what people are saying. If you don't do your

own research or listen to some of your own instincts too I think you can be steered down a certain path that I don't like.

P₂ also spoke to the importance of research and networking in order become aware of service options:

I think that's been a big one of realizing I need to actually look and find out [about services] and some of the best resources have been parents... The parent group that we have and some of them are saying we have this and the school is now using this because we asked for it, like, oh my gosh that would totally worked for my child.

Constituent 7, a need to be the expert on their child in order to communicate clearly with professionals regarding their child's unique needs and to determine which services are worth pursuing, appeared to be very closely linked Constituent 6, as reflected in P₂'s data

Earlier on you don't know, but you think [service providers] know what they are talking about, they know what he needs. There is an OT for goodness sake, she should be able to see what [my child] needs, but then I just, you realize, 'I think I actually know what [my child] needs maybe more than you do. Can I say that? Yeah, I think I can.' Without having the PhDs and all that. I'm with [my child] a lot of the time so I can tell.... I think you do have to, you go from, 'They know everything they're the experts' to going, 'Wait a minute. You don't know my child. You're not the expert, and I need to step in and say or quickly learn what I need to know so you know that I do know. What are those keywords that I should

have in my arsenal, the jargon that you want to hear to know that I actually do know what I'm talking about?'

P₂ went on to describe how beginning to see herself as the expert on her child and identifying the need to convey her expertise to service providers in a way they could receive meant that she needed to research and network effective ways of communicating with professionals about her child. This highlights another challenge faced by some caregivers with children with ASD: the burden of having to learn jargon used by professionals in order for some service providers to recognize caregivers as experts on their children. P₁ also endorsed facing similar challenges as she reflected on previous experiences with her child's teachers and other service providers:

Just because you are an educator does not mean you are always right. Here I thought like you are going to college, you know more than I do. I could not know as much as you know. I don't know as much as they know, but I know what's right for my child. Ultimately that's okay and whether they see it today, they might see it tomorrow, so I have to keep chugging along and believing in my child, because I know someday that he will be successful I just have to get him there, so I'm chugging on.

Lastly, Constituent 8, *fear regarding availability of future services and child's future after parents die*, is best reflected in the data of P₃ and P₅. P₃ shared her experience of this ongoing fear:

[My child] is a bit sensitive and I worry about him, if he's ever, if he is ever going to be able to take care of himself, because every parent with an autistic child...we all feel we can't die, we're not allowed to die. What's going to happen with our

kid? Are they going to be homeless? Is there anybody who's going to take care of them? It's a helpless feeling. ...I mean we take care of him, but what, I mean when we're no longer here, who is going to do that? Will he be able to do it for himself or does he need somebody? I don't know what's out there for people like him, adults with autism that don't have any parents anymore. I don't know what it is for them or where they live or what they do. For me, that's like a big question mark. What is there for them? I don't know.

P₅ shared a similar experience:

I'm still not sure what is going to happen. It's like if I go, if I end up dying tomorrow what's going to happen to him. I am scared because I don't have anything prepared for him. I have my mother that could take care of him and his dad, my husband, but still there is that unknown. What's going to happen to him? Are people going to treat him the same way that I treat him? Are they going to be loving and nurturing? So that's still my fear every day. I think that's the fear I have had since we've gotten diagnosed.

Issue subquestion 1: What is the psychological meaning of empowerment for parents' experiences going through the diagnostic and service utilization process for their child with ASD? The general structure reflecting the six participants' essential common features pertaining to issue subquestion 1 was as follows:

For the P experience of going through the diagnostic and service utilization process for their child with ASD, empowerment was characterized by P becoming increasingly aware of the limitations of state and service systems involved in service access and utilization. P also became increasingly aware of how power dynamics

between themselves, service providers, and service systems influence service access. P began to see themselves as an expert on their child and identified the need to be persistent in accessing services, while maintaining collaborative, positive relationships with providers. P engaged in continued research to stay informed about ASD, services, and service systems. P identified the importance and value of sharing their knowledge of services and resources with the ASD community. Lastly, P identified the importance and value of educating their community members about ASD and their child's needs, while also acknowledging that doing so requires energy P does not always have.

The following constituents comprised the general structure:

1. Awareness of the limitations of service systems and relevant power dynamics affecting service access and utilization.
2. Seeing self as expert on child.
3. Persistence in obtaining access to services and accommodations.
4. Engagement in research to stay informed about ASD, services, and systems involved.
5. Sharing knowledge with other parents/the ASD community.

Constituent 1 for this issue subquestion, *awareness of the limitations of service systems and relevant power dynamics affecting service access and utilization*, overlaps with Constituent 4 of the central research question, *awareness of challenges, barriers, and limitations in the service access and utilization process, leading to frustration and some distrust in service systems and service providers*. Constituent 1 of this issue subquestion differs in that this constituent captures the experience of awareness regarding systemic limitations and power dynamics specifically. Additionally, this constituent

captures awareness of how these limitations and power dynamics influence the experience of accessing services. P₂'s data reflects these experiences:

I can't wait for the professionals at school because they have limited resources. They have limited time with our child....But I think being able to try as much as we can foster good relationships goes so much further than just saying this is what my job needs to try to help knowing that you're the expert, but knowing that they're the professionals with the decision making power and being able to come and really try to protect those relationships, and make it positive or keep it positive.

P₂ discussed the importance of maintaining positive relationships with professionals, as she is aware they have "decision-making power" regarding accessing services. P₄ spoke specifically to her experience interacting with her caseworker, someone she perceived as the gatekeeper for accessing services:

I feel like you have to know the magical word to unlock the service you need. I still don't know them for some things. My friend said to me, "You need to be pointing out that [your child] doesn't sleep and she puts things in her mouth" because choking is huge...I was like, "Why does there have to be this magical code?" And if you don't use the right words, sometimes you don't get the right services... So, how are [other parents] going to know what the magical code word is? That's where it's frustrating.

P₄'s data highlights an awareness of the power differential between herself and her caseworker and identifies the burden of having to educate herself regarding what she felt was a "magical code" needed to unlock access to services. For example, she described

having to call a second meeting with her caseworker because in the first, she left out the word “choking” when listing her concerns about her child in making a case for receiving a personal service worker. As her friend informed her, “choking” was considered a code word that granted access to this service.

Constituent 2, *seeing self as expert on child*, overlaps with Constituent 7 of the central research question, *a need to be the expert on their child in order to communicate clearly with professionals regarding their child’s unique needs and to determine which services are worth pursuing*. While this constituent has already been discussed in regards to individual data, this experience is briefly captured in P₂’s data, “I think again just learning that there’s so much more out there than you realize and to ask questions. Not just go okay you’re the expert you’ll tell me everything I need to know.”

Constituent 3, *persistence in obtaining access to services and accommodations*, is reflected in the data of P₄ and P₆. P₄ described her experience learning the importance of persistence in obtaining services for her child:

I will say you have to be persistent. You have to push a lot, and if you are not used to that it’s hard. Like I got used to it...I realized okay, I have to be pushy. I have to regularly, I hear from parents, who say, “Oh my God, [Developmental Disability Services] took 6 months.” There is no way I’m going to let it take 6 months. I showed up at the door, I would call regularly. If I didn’t get one of them I would show up, I would be like, “Can I see the supervisor?” So, if you don’t do that, you can get lost in the system. You have to keep pushing. I don’t blame [the caseworkers] as much, I know they are overtaxed. It’s so much need, not enough people, not enough resources. But I feel like if you don’t push you are not going

to get what you need. So, in that way you are always pushing too as a mom, or as a parent.

P₆ also described a need to be determined and persistent in finding services for her child.

When asked what helped her be persistent, she explained:

I think I just was determined to help my child. I think that was my main motivating factor of whether I sought out services or someone who could help me or someone who could refer me to someone who could help me was just because I wanted to help my child. I didn't want to be helpless and I had an awareness of all the things that I have done personally that there are services out there, there are so many services out there.

Constituent 4, *engagement in research to stay informed about ASD, services, and systems involved*, overlaps with Constituent 6 of the central research question, *engagement in ongoing research and networking to learn about available services and pathways to utilization*, which has already been discussed in regards to individual participant data.

Constituent 5, *sharing knowledge with other parents/the ASD community*, has some overlap with Constituent 6 of the central research question, *engagement in ongoing research and networking to learn about available services and pathways to utilization*.

While both share the experience of networking with other parents in order to obtain information and resources, Constituent 5 of this issue subquestion also adds in the experience of sharing and exchanging information and resources in order to help others.

P₄'s data reflects this reciprocity:

So, I think the way that I end up getting around is I speak to tons of people and I ask a lot of questions of the parents. Parents are an amazing resource, because somebody out there has been through similar what you are going through. I try for my part to throw out what I know when people ask questions and say well, we had to fight this way or use this word because I have seen that.

P₆'s data underscores the positive psychological experience associated with sharing knowledge with other parents of children with ASD.

I'm really pleased that I have connected at this point however tardy in the timeline of things with these services. Because through my experiences I can better educate other people as I meet them and as I network with them I can say, "Oh have you heard about blah, blah, blah," and at least direct them to another person who might be able to open up more possibilities for them.

Issue subquestion 2: What is the psychological meaning of advocacy for parents' experiences going through the diagnostic and service utilization process for their child with ASD? The general structure reflecting the six participants' essential common features pertaining to issue subquestion 2 was as follows:

For the P experience of going through the diagnostic and service utilization process for their child with ASD, advocacy was characterized as P coming to see themselves as the expert on their child, an active and critical component of the service access and utilization process. P engaged in a process of constantly working to figure out what is best for their child, persistently asking for services and accommodations as needed, and continuously educating their service providers and community members about their child's specific needs.

The following constituents comprised the general structure:

1. Seeing self as expert on child with an active role in the service utilization process
2. Educating/engaging community members regarding advocacy efforts.

Constituent 1, *seeing self as expert on child with an active role in the service utilization process*, shares similarities with Constituent 2 of the first issue subquestion, *seeing self as expert on child*, as well as Constituent 7 of the central research question, *a need to be the expert on their child in order to communicate clearly with professionals regarding their child's unique needs and to determine which services are worth pursuing*. Constituent 1 of this issue subquestion is set apart from the other constituents by incorporating the experience of seeing the role as expert with an active role in the service utilization process as part of being a caregiver. In other words, parents are seeing themselves as advocates for their children. P₄'s data reflects this experience:

So, I had to get to a place of like all right, this is what we do. We are going to make her as independent as possible. But my guess is I will still be advocating for her when she is older. Or I will be helping her advocate for herself. So, I think maybe I resigned to it is the answer. I just feel like all right, this is part of what we do now. We have to repeatedly call people. We have to say, "Hey, when are we in?" It doesn't really bother me and it's funny because I would say in my 20s I would have been so like shocked back and had a hard time. Now I just feel like, there is something about it when it's your child. You're like we've got to do this, we've got to fight for this or we're going to get lost.

P₂ also speaks to this experience of seeing themselves as an expert and advocate:

I just really learn that I have to push for it. I'm not naturally like this is what we need. So, I'm sure they get that and that's hard for them to, so trying to do it and be a team about it and so we had some interesting moments because it took a while for me to realize and go, oh no I actually really have to say, "Okay I can call another IEP meeting," but I know that's tough to do. And we had a couple this year. I hate, I express like I would love to just work this out together, but if we need it in writing we can do that... I'm not a conflict lover, but it just taught me that you have to, there are ways to be able to work through things and you can't give up because you are the best advocate that you can have and you do know [your child] well.

Constituent 2, *educating/engaging community members regarding advocacy efforts*, shares similarities with Constituent 5 of the first issue subquestion, *sharing knowledge with other parents/the ASD community*, and with Constituent 6 of the central research question, *engagement in ongoing research and networking to learn about available services and pathways to utilization*. Constituent 2 is set apart by incorporating the experience of engaging with others in advocacy efforts and larger systemic change. P₆ described the experience of educating others in how to advocate for change:

You are also teaching people, as I do with [my child], teaching people to advocate for themselves. If this isn't working try something else. Ask another person. Ask 7 other people. I've been doing that with [my child], and I have been encouraging him to ask for what he wants, "If this isn't working for you, you need to tell people how it can."

P₄'s data captured the experience of educating and engaging others in advocacy efforts for systemic change:

I think that for me, turning outwards to all these other moms has made it better for me and helping to start the A Team has made it better for me too. Like, I don't feel that feeling of like, I don't feel, 'Oh this is me, this is so hard.' I feel more like, 'What are we going to do here and how do we band together and make ourselves heard?' because the reality is it's always parents. Mental institutions, they close down for parents, Mothers against Drunk Driving. I feel like it's often parents who say, "We are tired of this." I feel like that's still going to have to keep happening and we are going to I think, there are still things that I see that are messed up. But for me I don't feel lost. I feel more like, I think I feel empowered by what we have chosen to do. There is no other word.

Additional question: What recommendations do interviewed parents have regarding the diagnostic and service utilization processes for other parents, service providers, and policy-makers? To address this additional research question, participants were asked "What recommendations, if any, would you give to a parent that just received a diagnosis of ASD for their child?" during the second qualitative interview. Responses to this question as well as any recommendations for other parents, service providers, and service systems that were offered spontaneously were coded during data analysis. Emergent themes in the responses coded as recommendations are summarized and presented in Table 5.

Table 5

Emergent Themes in Parent Recommendations Across Ecological Levels

Ecological Level	Recommendation Theme
Microsystem	<p>Parents need to be willing to “push” and “fight” for their child to access services.</p> <p>Parents need to be collaborative to maintain positive relationships with service providers.</p> <p>Parents need to do research regarding available services and resources.</p> <p>Parents need to learn from their child directly to become the “expert” on their child.</p> <p>Parents need to ask for help and find sources of emotional and logistical support.</p>
Mesosystem	<p>Service providers need to be attentive to family dynamics and needs.</p> <p>Service providers need to view parents as experts on their children.</p> <p>Service providers need to use a positive/strengths-based approach.</p> <p>Service providers need to be a resource for knowledge on ASD and service options.</p> <p>Service providers need to be able to advocate for families struggling to access services.</p>
Macro/Exosystem	<p>There needs to be more funding to increase service options, accessibility, and consistency.</p> <p>There needs to be more consolidation and organization of services to increase continuity of care.</p> <p>There needs to be shorter wait times and simpler pathways to accessing services.</p> <p>There needs to be more access to information regarding service and treatment options.</p>

CHAPTER V

DISCUSSION, RECOMMENDATIONS, AND IMPLICATIONS

The purpose of this integrated phenomenological study was to examine and understand parents' psychological experiences obtaining a diagnosis and accessing services for their child with ASD. Participant data from Wave II of a larger longitudinal study were used for the quantitative exploratory descriptive analysis. Purposeful sampling was used to recruit participants from the larger sample to be included in the phenomenological qualitative interviews and explore and understand participants' experiences in-depth. In this chapter, the results presented in chapter four are discussed in the context of the existing literature, highlighting the unique contributions of this research and the literature confirmations and contradictions concerning the participants' lived experiences. I then explore the recommendations and implications for practice across levels of the ecological model and make suggestions for future research. Parent recommendations presented in Table 5 are incorporated into the recommendation and implication section.

It should be noted here that the scientific phenomenological reduction is a partial reduction. That is, as the results are contextualized within "a worldly subjectivity that is influenced by society, culture, others, and the world at large" (Giorgi, 2009, p. 135). Even though every participant's description is different, the psychological meanings can be similar, which allows for the integration of data from multiple participants into one general structure. I attribute these consistencies in the data can be attributed to similarities in ecological features across participants- shared individual, situational, and societal factors that interact and influence each other to produce similar psychological

experiences. An exploration of the impact of each ecological factor on the similarities between participants is beyond the scope of this study, however, in this chapter, I do discuss results and implications with attention to the bidirectional ecological systems that contextualize the data.

Central Research Question: What is the Lived Psychological Meaning of Parents' Experiences Going Through the Diagnostic and Service Utilization Process for their Child with ASD?

The exploratory descriptive quantitative analyses indicated that of the six interviewed participants, two reported not having enough money to get by, and four reported just enough to get by. The mean approximate family income for this subsample was \$32,000.00 ($SD = 9,219.5$), with five reporting incomes at 150% of the Federal poverty line or below and one reporting incomes above 150% of the Federal poverty line. According to Thomas et al. (2007), families living in nonmetropolitan areas and those with limited education achieve only limited access to care for ASD. Despite being a relatively low-income sample inhabiting a non-metropolitan geographic area, the phenomenological analysis did not indicate that financial strain was an explicitly cited critical or essential aspect of the caregivers' experiences obtaining a diagnosis and accessing services. It is possible that Constituent 4 (*awareness of challenges, barriers, and limitations in the service access and utilization process, leading to frustration and some distrust in service systems and service providers*), Constituent 6 (*engagement in ongoing research and networking to learn about available services and pathways to utilization*), and Constituent 7 (*a need to be the expert on their child in order to communicate clearly with professionals regarding their child's unique needs and to*

determine which services are worth pursuing) may indirectly reflect experiences influenced by SES factors, such as income and educational attainment. That is, limited finances may constrain treatment options and lower levels of education may add challenges to the process of researching ASD. According to Perry (2013), level of education is related to empowerment such that lower educational attainment is associated with less empowerment skill and knowledge.

At the time of the Wave II interview, satisfaction with current services among the six caregivers, like that of the larger sample, was between neutral and somewhat satisfied. This minimal self-reported dissatisfaction in survey data aligns with previous research. Montes, Halterman, and Magyar (2009) found that only 19.8% of the 2,123 parents of children with ASD surveyed reported dissatisfaction with current services, despite simultaneously reporting experiencing multiple challenges and barriers to accessing and utilizing services for their child (long wait times, transportation issues, unmet needs, etc.). Similarly, Bitterman, Daley, Misra, Carlson, and Markowitz (2008) found that while only 13.2% of parents with ASD reported being dissatisfied with the overall quality of current services, 47.1% reported dissatisfaction with the amount of services provided and 25.1% reported needing services not already received. While most parents may not report overall dissatisfaction with services received, they do report specific challenges, barriers, and aspects of service delivery that they are dissatisfied with.

Discussion of constituents. Some elements of Constituent 1, *uncertainty regarding what a diagnosis of ASD means and what will happen next in regards to child functioning and services*, are reflective of prior findings. In several studies, parents with children with ASD report experiencing a lengthy, complex, and discouraging assessment

and diagnostic process in which parents describe feeling frustrated, confused, disempowered, and overwhelmed (Ahern, 2000; Mulligan et al., 2012; Schall, 2000). Mulligan et al. (2012) also found that feeling overwhelmed with information and emotion at time of diagnosis, as well as processes of grief, relief, and making sense of ASD, were common themes for parents of children with ASD. While the caregivers in the present study also endorsed feeling confused and overwhelmed with uncertainty and how to make sense of ASD, they did not describe other negative psychological experiences reflected in the literature (e.g. grief, discouragement). It is possible that because interviews regarding experiences with the diagnostic process in the current study took place several years after the actual time of diagnosis, parents may have been farther along in their process of grief and acceptance in response to diagnosis than parents in other studies. A few parents in the present study had difficulty recalling specific emotional and psychological experiences from the time of diagnosis, stating that the whole process felt like a “blur.”

Constituent 2, *increased access to services and information regarding ASD and available services following a diagnosis*, echoes the existing literature. According to Woods and Wetherby (2003), many children are not able to access early interventions in a timely manner without a diagnosis. Given early intervention is critical to improving outcomes, obtaining a diagnosis can serve as a gateway for accessing services and information regarding ASD for parents. This seemed to be reflected in participant responses such that obtaining a diagnosis resulted in an increase in access to services for their child with ASD.

Constituent 3, *relational strain and frustration with people in social support network that misunderstand ASD and/or judge parent for their child's ASD behavior*, was both supported and contradicted by the mixed results in the literature. In data collected from the 2007 National Survey of Children's Health, a population-based, cross-sectional survey of 77,911 parents with children aged 3–17 years, there was no evidence to suggest that children with ASDs are at an increased risk for living in a household not comprised of their two biological or adoptive parents compared to children without ASD in the United States (Freedman, Kalb, Zablotsky, & Stuart, 2012). In the subsample of six participants, three underwent a separation or divorce from a domestic partner or spouse. Despite no cross-sectional differences in divorce rates in the national study, there may be differences in divorce rates over time. According to a longitudinal study comparing parents of children with ASD to parents of children that are typically developing, however, parents of children with ASD have a higher divorce rate than those with typically developing children (23.5% vs. 13.8%; Hartley, 2010). The authors also found that the rate of divorce remains high throughout childhood, adolescence, and early adulthood for parents of children with an ASD, whereas it decreases after their children reach 8 years of age for the comparison group. Despite the mixed findings that exist in the literature, the data in the present study suggest that marital and other familial or relational strain is a critical component of the experiences of parents of children with ASD.

In regards to perceived judgement and stigma, a sociological study examining the experiences of stigma in 53 parents of children with ASD found that just over three fourths of parents interviewed experienced “felt” stigma, identified as perceptions that

others were critical of their child-raising abilities, not accepting of them, and made them feel embarrassed (Gray, 2002). Additionally, just over half of the parents had encountered “enacted” stigma, including avoidance, hostile staring, and rude comments from others. The author noted that parents often had difficulty differentiating between felt and enacted stigma, such that both forms often merge in the experiences of the parents (Gray, 2002). Parents in the present study described experiencing both felt and enacted stigma within family relationships as well as in public social situations (grocery stores, restaurants, etc.). Derguy, M’Bailara, Michel, Roux, and Bouvard (2016) found that tense extended family relationships were associated with higher self-reported stress in parents with children with ASD. While relational stress within the nuclear and extended family seemed to be a critical theme for the parents interviewed in the present study, participants did not explicitly describe associations between relational strain and parental stress.

Constituent 4, *awareness of challenges, barriers, and limitations in the service access and utilization process, leading to frustration and some distrust in service systems and service providers*, is consistent with the findings of several other studies. Parents of children with ASD often report lack of service and treatment availability (Goodwin, Intille, Albinali, & Velicer, 2011) with 75% of parents reporting that they are unable to access necessary medical, educational, and recreational services for their child with ASD (Goodwin et al., 2011). In a qualitative study examining parents’ experiences obtaining a diagnosis and accessing services for children with ASD, a common theme was parents’ desire for coordinated services before, during, and following their child’s diagnosis, as they had difficulties “navigating the system” (Martos, 2013). This finding was reflected in caregiver responses in the current study. Overall, interviewed caregivers in the current

study reported experiencing challenges and barriers to service access and utilization, including long wait times, uncoordinated services, and lack of information regarding services available. As a result, caregivers in the current study experienced anger, frustration, and distrust in caseworkers, service providers, and the systems involved in service utilization pathways.

Several studies have reported that lack of time, insufficient reimbursement, and staffing are major barriers to adhering to best-practice guidelines for clinicians (Lord & Bishop, 2010; Sand et al., 2005; Sices, Feudtner, McLaughlin, Drotar, & Williams, 2003). Some caregivers in the present study did reflect awareness of these larger systemic issues, including P₄, P₅, and P₆'s responses discussed within Constituent 4, *awareness of challenges, barriers, and limitations in the service access and utilization process, leading to frustration and some distrust in service systems and service providers.*

Participants' responses corresponding to Constituent 5, *a desire and/or appreciation for sources of support and information regarding services: collaborative, strengths-based service providers and communities of other parents of children with special needs*, emphasized the importance of and desire for positive relationships with service providers. Their responses also indicate that service providers function as a resource for information regarding services and as advocates to help caregivers access services in a strengths-based, collaborative way. Mulligan et al. (2012) found that parents of children with ASD demonstrated a preference for diagnostic information in a hopeful tenor. In addition, parents indicated a need for support, information, resources, and tools for navigating the complexity of service/treatment options (Mulligan et al., 2012). Martos (2013) found that in addition to parent-clinician interactions, family, social, and

community supports also affected parents' ability to access and utilize services. This is consistent with some parents' expressions of appreciation for an online community of parents with children with ASD, in which they described turning to this community as a resource of information and support.

Both Constituent 6, *engagement in ongoing research and networking to learn about available services and pathways to utilization* and Constituent 7, *a need to be the expert on their child in order to communicate clearly with professionals regarding their child's unique needs and to determine which services are worth pursuing* seem to align with existing research. Minnes, Nachshen, and Woodford (2003) found that the roles of parents with children with ASD have expanded to include the jobs of "information seeker, problem solver, committee member, public educator, political activist and, most importantly, spokesperson for the needs of their children" (p. 665). In a metasynthesis of qualitative research on parents of children with ASDs. DePape and Lindsay (2014) also found that two major themes of parenting a child with ASD were a) parents educating themselves about ASD and ASD-related services and b) coming to see themselves as experts. The authors conceptualized both of these themes as aspects of parental empowerment in their study.

Lastly, is Constituent 8, *fear regarding availability of future services and child's future after parents die*. While a specific fear related to caregiver death was not found in the literature pertaining to parents of young children with ASD, fears regarding future functioning and access to services through adulthood was found in the broader literature on parents of older children with intellectual and developmental disabilities. One qualitative study found that a major theme for parents of children with ASD transitioning

from school to adulthood was fear associated with learning how to navigate the adult agency support systems for their child (Cooney, 2002). Other researchers have identified similar parental concerns, including identifying residential living options, determining available employment opportunities, and finding available agency assistance (Bianco, Garcia-Wade, Tobin, & Lehmann, 2009; Chambers, Hughes, & Carter, 2004; Cooney, 2002). In a metasynthesis of qualitative research on parents of children with ASDs, DePape and Lindsay (2014) also found that parental concerns regarding future functioning and achievement of typical life stage milestones (career, marriage, etc.) was a common theme.

Constituent 8 is closely linked to Constituent 1, *uncertainty regarding what a diagnosis of ASD means and what will happen next in regards to child functioning and services*. Both constituents emphasize the fear and uncertainty associated with the unknown, particularly in regards to their children's future. These are also both connected to Constituent 4, *awareness of challenges, barriers, and limitations in the service access and utilization process, leading to frustration and some distrust in service systems and service providers*, in the sense that caregivers indicated a lack of information regarding services available across the lifespan for their children as well as the limitation of uncoordinated care. This contrasts with Constituent 2, the experience of *increased access to services and information regarding ASD and available services following a diagnosis*, and underscores the importance continued and coordinated care. This is linked to Constituents 6 and 7, in which caregivers indicated a need to take it upon themselves to research available services, network with other parents of children with ASD, and see themselves as the experts on their children in order to discriminate between service

options. In the parents' descriptions, there is also a connection to Constituent 3 in that for some, there was a worry that people may not understand their child with ASD. For several parents, there was a concern regarding limited sources of support after they die, and desire for social supports and services for their children after they die, which relates to Constituent 5, *a desire and/or appreciation for sources of support and information regarding services: collaborative, strengths-based service providers and communities of other parents of children with special needs.*

Issue Subquestion 1: What is the Psychological Meaning of Empowerment for Parents' Experiences Going Through the Diagnostic and Service Utilization Process for their Child with ASD?

The exploratory descriptive quantitative analyses indicated that for the subsample of six participants, the mean Family and Service System subscale scores were similar, 51 and 50.7 respectively, with a highest possible score of 60. Data from other studies utilizing FES subscale scores were not available; therefore I am unable to compare these means to other samples in the literature. Despite the lower mean score on the Community/Political subscale, 34, it is important to note that the lower mean is not necessarily reflective of lower empowerment in that domain because the score range is more constricted. Compared to the whole Wave II sample, the subsample of interviewed participants scored similarly on all subscales of empowerment. According to Perry (2013), gender and level of education were related to empowerment such that mothers and parents who attended college were independently more likely to report higher levels of empowerment than fathers and parents who had not attended college, respectively. The interviewed sample consisted entirely of female caregivers with a mean of 14.2 years of

education. While the entire Wave II sample also consisted of all female respondents (with male caregivers present at two interviews), the mean years of education was 15.1. While significance testing between the Wave II sample and the subsample fell outside of the scope of answering the research questions, it appears that there were no remarkable differences in empowerment for the subsample compared to the entire Wave II sample. Furthermore, empowerment in the Wave II sample was not correlated with other variables, which may be due to small sample size. It is possible empowerment simply did not vary in conjunction with demographic variables.

Discussion of constituents. Constituent 1 for this issue subquestion, *awareness of the limitations of service systems and relevant power dynamics affecting service access and utilization*, was congruent with the findings of Carlsson, Miniscalco, Kadesjo, and Laakso (2016). The authors also found that an awareness of systemic limitations was an emergent theme for parents of children with ASD post-diagnosis. Parents in the study indicated that timing of resources, in particular, was an area ripe for improvement. Parents also indicated that navigating the balance between trusting and challenging those in with authority (service providers) was an important theme in their experiences following a diagnosis.

Constituent 2, *seeing self as expert on child*, overlaps with Constituent 7 of the central research question, *a need to be the expert on their child in order to communicate clearly with professionals regarding their child's unique needs and to determine which services are worth pursuing*. As such, it has already been discussed in regards to relevant literature.

Constituent 3, *persistence in obtaining access to services and accommodations*, was echoed in the literature. One of the emergent themes from a study examining experiences post-diagnosis for parents of children with ASD was feeling as though parents had to continuously “fight” for their children in order to access resources. This constant struggle for resources and for help from providers was found to be tiresome, frustrating, and time consuming (Carlsson et al., 2016). Similarly, Cooney (2002) found that parents of children with ASD transitioning from school to adulthood experienced frustration with the inability to secure necessary supports for their child in a timely manner. This frustration in navigation service utilization pathways was also endorsed by the participants in the present study, as discussed within other constituents.

Constituent 4, *engagement in research to stay informed about ASD, services, and systems involved*, overlaps with Constituent 6 of the central research question, *engagement in ongoing research and networking to learn about available services and pathways to utilization*, which has already been discussed in regards to relevant literature.

Constituent 5, *sharing knowledge with other parents/the ASD community*, has some overlap with Constituent 6 of the central research question, *engagement in ongoing research and networking to learn about available services and pathways to utilization*. Parents of children with ASD experience higher levels of stress than those of typically developing children (Derguy et al. 2016), with perceived social support being negatively associated with stress for these parents (Derguy et al. 2016; Falk, Norris, & Quinn, 2014). Furthermore, mothers of children with ASD consider giving and receiving support to other mothers of children with ASD as daily positive events (Smith et al., 2010). The parents

interviewed in the present study also indicated that sharing resources and providing support were positive experiences.

As defined previously, empowerment is “the process by which people, organizations, or groups who are powerless (a) become aware of the power dynamics at work in their life context, (b) develop the skills and capacity necessary for gaining some reasonable control over their lives, (c) exercise this control without infringing upon the rights of others, and (d) support the empowerment of others in their community” (McWhirter, 1991, p. 224). For caregivers of children with developmental disabilities, a parent's active agency and sense of control extends beyond themselves to include their child and their family (Nachshen, 2005). Component (a) of the definition above, becoming aware of power dynamics at work in their families’ life context corresponded to Constituent 1, *awareness of the limitations of service systems and relevant power dynamics affecting service access and utilization*. Component (b) of empowerment corresponded best to Constituents 2 and 4, *seeing self as expert on child and engagement in research to stay informed about ASD, services, and systems involved*, such that these constituents laid the foundation from which participants develop the skills and capacity necessary to gain some reasonable control over their own and their families’ lives. Component (c) corresponded to Constituent 3, *persistence in obtaining access to services and accommodations*, such that the persistence in obtaining services and accommodations was the method by which parents could exercise this control without infringing upon the rights of others. Lastly, component (d) corresponded to Constituent 5, *sharing knowledge with other parents/the ASD community*, in which sharing knowledge

with others is in effect supporting the empowerment of other parents with children with ASD.

Issue Subquestion 2: What is the Psychological Meaning of Advocacy for Parents' Experiences Going Through the Diagnostic and Service Utilization Process for their Child with ASD?

While there was no direct measure of advocacy in the Wave II data collection materials, Koren and colleagues (1992) found that parents' level of empowerment discriminated between parents involved in advocacy-related activities, such as advisory and political activities, and those who were not involved, which aligns with the conceptualization of advocacy as a behavioral manifestation of empowerment (Nachshen, 2005). As such, there was significant overlap between the constituents comprising parents' experiences of advocacy and experiences of empowerment.

Discussion of constituents. Constituent 1, *seeing self as expert on child with an active role in the service utilization process*, shares similarities with Constituent 2 of the first issue subquestion, *seeing self as expert on child*, as well as Constituent 7 of the central research question, *a need to be the expert on their child in order to communicate clearly with professionals regarding their child's unique needs and to determine which services are worth pursuing*. Mulligan and colleagues (2012) found that parent-identified themes associated with diagnosis included becoming an advocate, expert, and case manager. One qualitative study investigated parents' perceptions of the roles they played in their children's lives during the post-high school years; findings indicated that parents perceive being an advocate is critical a role they play for their adult children. More specifically, roles parents assumed as their children entered into adult life were those of

collaborators, decision makers, and program evaluators, role models, trainers, mentors and instructors, and systems change agents (Bianco et al., 2009). Despite the relatively young age of the children with ASD in the present study, these themes and perceived roles are reflected in the participants' data that comprise this constituent. Furthermore, participants' data suggests that parents' self-concept changes through the processes of obtaining a diagnosis and accessing services, such that that they see themselves transforming into more powerful people than they otherwise would have been, as a result of the ASD experience. Their perceptions of who has valuable expertise also appears to shift, as they come to see that providers' knowledge may be limited, and that parents may know more than originally thought. This shift may be an important step in the process of becoming an advocate for their children.

Constituent 2, *educating/engaging community members regarding advocacy efforts*, shares similarities with Constituent 5 of the first issue subquestion, *sharing knowledge with other parents/the ASD community*, and with Constituent 6 of the central research question, *engagement in ongoing research and networking to learn about available services and pathways to utilization*. Participants' data make the connection between advocacy and empowerment explicit; through involvement in advocacy work, they feel empowered. This corresponds with Mickhail's (2010) findings that parent-driven "communities of support," or groups of parents that facilitate parental empowerment and advocacy for their child with ASD, can create lasting change in schools and communities in regards to availability and access to services.

A recent thematic metasynthesis of qualitative studies on parents of children with ASDs identified six key stages of parenting a child with ASD: prediagnosis, diagnosis,

family life adjustment, navigating the system, parental empowerment, and moving forward (DePape & Lindsay, 2014). With the exception of prediagnosis, all other stages corresponded with emergent constituents in the present study. Within the stage of diagnosis in DePape and Lindsay's study, they found mixed emotional responses to receiving an ASD diagnosis, including relief, devastation, guilt, and blame. Several parents in the present study also expressed devastation as well as relief at having more answers and support as a result of obtaining a diagnosis. Within the stage of family life adjustment, the DePape and Lindsay (2012) found subthemes of stress associated with managing daily routines, relational strain, and social stigma/judgment from others. Each of these was described by the mothers in the current study as well. In DePape and Lindsay's study, the stage of navigating the system was characterized by experiencing challenges within the school system and in accessing treatment, including financial strain, insufficient communication with providers, and generally unsupportive teachers and providers. DePape and Lindsay's results highlight the importance of having collaborative parent-professional relationships, which was also highlighted in the data from the present study. DePape and Lindsay (2012) found that parents often reported educating themselves about ASD and implementing strategies that worked for their family. This empowerment led to parents challenging the information about ASD they received from others and it gave them some sense of control over their lives. Parents in the present study also emphasized the importance of educating themselves, seeing themselves as experts on their children, and challenging professionals and service providers in order to advocate for better access to services for their children with ASD. Lastly, the DePape and Lindsay (2012) found that the stage of moving forward was characterized by a process

through which parents accepted their child's diagnosis and also wondered about the long-term outcomes for their son or daughter with ASD. Several parents in the present study also voiced acceptance for their child and expressed fear regarding future functioning through Constituent 8, *fear regarding availability of future services and child's future after parents died*. Even though this theme was not specifically found as a critical theme in other studies examining parents' experiences of the diagnostic and service utilization processes, it was found in the broader qualitative literature examining experiences across the lifespan for parents with older children with ASD and other DDs. Given all the emergent constituents, or themes, echoed those of other studies with similar research questions, there does not seem to be a significant difference in the experiences of the interviewed participants in this study compared to others.

Limitations

As with any research study, there are limitations that must be considered in interpreting the findings. Because the analysis ultimately rested with my thinking and choices, this study was limited by researcher subjectivity. Researcher bias influences how assumptions, interests, perceptions, and needs are framed. As such, this limitation was addressed by engaging in the ongoing process of critical self-reflection, openly acknowledging my biases, and having debriefing sessions with a peer and colleague, the Devil's Advocate. Even with these elements in place, it is possible that researcher bias influenced my conclusions in ways that are outside of my awareness.

In regards to the study's integrated methods, one important critique to consider comes from Yanchar and Williams (2006). When researchers view eclectic, or integrated, methodology as useful and unproblematic, a dangerous and potentially unscientific

practice takes place in which research is then guided by unexamined ideas and values. Without critical reflection on how the underlying assumptions shape results, readers are not made aware of what potential insights may be concealed or distorted by even the most well-intentioned research and evaluation efforts. Only when underlying assumptions have been subjected to critical examination can researchers be confident in using defensible and promising research strategies. I invested consistent effort in remaining flexible, critical, and theoretically informed regarding inquiry practices. The suggested five C's of implementing integrated designs outlined by Yanchar and Williams (2006) were also be incorporated: (1) Contextual sensitivity, or tailoring the use of multiple methods to the contextual demands, problems, and subtleties of the research questions; (2) Creativity in theory construction, question formulation, and problem solving throughout the research process; (3) Creative adaptation of existing methods and tools to the extant necessary for a thorough, direct, and fruitful interrogation of the subject matter in a given context; (4) Conceptual awareness, or an acknowledgement that methods are inextricable from underlying assumptions and an appropriate emphasis on the theoretical nature of methods being used by identifying underlying values, assumptions, and theoretical commitments that have practical and theoretical consequences; (5) Coherence in describing theories, methods, questions, data analysis, and criteria for success; and (6) Critical reflection.

Another limitation of this study was that the research sample was restricted. Phenomenological data was collected from a sample of six participants over a short time frame, which does not provide a longitudinal understanding of the participants' experiences. The longest time span from the first to the last interview was 10 weeks.

Although purposeful sampling was utilized to recruit families from low SES and ethnic minority backgrounds, the purpose of this study is not to be able to generalize to all individuals who inhabit the intersection of these identities. Issues of race, SES, and ethnicity (as well as other under-represented identities) were not explored in a way that would give justice to the intersection of the various dimensions of their personal or group identities. In general, the quantitative and demographic data from interviewed participants aligned with the Wave II data, and the results are mirrored in the existing literature.

Because data are from caregivers' reports of their lived experiences, I did not have data from other perspectives, which may have helped in triangulation. Additional data from social workers, caregivers, teachers, and other service providers may be useful in further triangulating the findings within this study; this could add further context and information regarding the processes and experiences involved for parents' obtaining diagnoses and services for their children with ASD.

Recommendations and Implications

The additional recommendations question, "What recommendations, if any, would you give to a parent that just received a diagnosis of ASD for their child?" was incorporated in order to address the final procedural subquestion (Giorgi, 2009; 2012) guiding this study, "What implications do the psychological structure of these experiences have for mental health professionals, service providers, and policy-makers?" This additional question was also a deliberate strategy to elicit parental knowledge for the benefit of others as a way of supporting parent empowerment and acknowledging their strengths. Additionally, any recommendations for other parents, service providers, and

service systems that were offered spontaneously by the parents were coded during data analysis. Their recommendations, presented in Table 5, are organized by levels of the ecological model and discussed in this section along with study implications. This section concludes with implications for future research.

Microsystem. At an individual level, parents interviewed encouraged other parents of children with ASD to “push” and “fight” for their child while also being collaborative and maintaining positive relationships with service providers. Parents also recommended that other parents of children with ASD do their own research regarding services and resources available while also learning from their child directly in order to become “the expert” on one’s own child. The quote, “if you know one child with autism, then you only know one child with autism,” was used by several participants in the interviews, in reference to the diverse presentation of symptoms and level of functioning captured under the diagnosis of ASD. Lastly, parents recommended that other parents ask for help and find sources of emotional and logistical support for going through the service utilization process. Some participants even stated they would offer up their own contact information and would meet with another mother of a child recently diagnosed with ASD in order to “just listen” or “share resources.” These recommendations align with findings that parents’ experiences of empowerment and advocacy influence parents’ decision-making process and lead to lower self-reported parental stress and higher quality of life (Martos, 2013; Minjarez, 2012; Nachshen & Jamieson, 2000; Weiss et al., 2014). The results of the present study are consistent with existing literature and suggest that parents of children with ASD may be exhausting a significant amount of their limited time and energy to persist in the struggle to access services while negotiating important

relationships with providers. Additionally, parents may benefit from having identified sources of emotional and logistical support, and from shifting their self-concept to that of a critical consumer of services and expert on their child.

Mesosystem. Participants in this study found navigating the treatment selection process to be challenging and confusing. At the mesosystemic level, participants shared recommendations for service providers working with caregivers of children with ASD. Parents overwhelmingly shared a desire and appreciation for collaborative relationships with service providers (see Constituent 5 of the central research question). Common characteristics of these collaborative relationships, as expressed by the participants, included: being attentive to family dynamics and needs, seeing parents as the expert on their child, being strengths-based, serving as a resource of knowledge on ASD and service options, and being an advocate for families struggling to access services. These recommendations also align with findings in the literature indicating that empowering parent-professional relationships are associated with more positive experiences for families as well as more effective service delivery (Van Ryn & Heaney, 1997).

In supporting parents as they navigate the treatment selection and service utilization processes, clinicians need to have an understanding of the issues that might impact caregivers' decisions. This understanding could foster the development of more collaborative relationships and would allow professionals to recommend interventions that would address symptoms most concerning to caregivers while using a family-centered care (FCC) approach (Hebert, 2014).

Hodgetts, Nicholas, Zwaigenbaum, and McConnell (2013) define FCC as a broadly defined practice philosophy in which parents and service providers work in

partnership. Supports and services coincide with changing needs and priorities of the family, and families are given choice and control over treatment decisions. Research suggests FCC is associated with increased parent satisfaction, decreased parent stress, and improved child outcomes (King, King, & Rosenbaum, 2004; Woodside, Rosenbaum, King, & King, 2001). Based on the recommendations from parents in the current study, an FCC model might be well received and helpful in fostering positive, family-centered, collaborative parent-professional relationships in which parents are valued as experts on their children.

A similar empirically supported approach for establishing positive relationships and collaboration between caregivers and professionals is the Shared-Decision Making approach (SDM). A health professional using SDM engages in a dialogue about the family's preferences, values, concerns, quality of life, and the child's symptoms, offering information regarding potential out-comes, risks, and benefits of each treatment option. With SDM, the health professional and the family jointly develop and agree on a treatment plan for the specific needs of each child and their family (Charles, Gafni, & Whelan, 1997; Golnik, Maccabee-Ryaboy, Scal, Wey, & Gaillard, 2012). SDM is especially helpful when no one best treatment option is indicated and certainty is low, as is frequently the case for parents facing treatment options for their child with ASD (Golnik et al., 2012; Whitney 2003). Parents in the current study experienced difficulties navigating different service options, and indicated that an important part of collaborative parent-professional relationships was having professionals serve as a resource on ASD and service options. This SDM model may be helpful for improving collaborative parent-professional relationships.

Both FCC and SDM emphasize the importance of sharing power and collaborating with caregivers when it comes to treatment planning. Parents in the present study expressed appreciation for collaborative relationships with professionals and providers. According to Golnik et al. (2012), parents that report feeling like they are part of the decision making process report feeling more satisfied their child's care. In addition, health professionals must also be able to employ creative approaches to meet the needs of the diverse families they serve. This involves a more active and direct role in joining with families and inviting them to engage collaboratively in the treatment planning process. It is also important for family counselors and other mental health professionals to be aware of and actively utilize multicultural competencies (personal awareness, cultural knowledge, and appropriate skills; Sue & Sue, 2012) and advocacy competencies (Lewis, Arnold, House, & Toporek, 2002) to support families living with ASD (Enis-Cole, 2013).

Macro and Exosystem. On a broader systemic level, interviewed participants indicated that funding for services seemed to be lacking and inconsistent. Parents also indicated that continuity of care is lacking, such that services need to be consolidated and be offered in such a way that children can continuously receive services across the lifespan. More specifically, parents expressed a desire for shorter wait times and simpler pathways to access services. They also indicated a need for more access to information regarding service and treatment options. One parent recommended that a resource binder or webpage with consolidated, up-to-date information on available services and descriptions of how to access them would be a significant improvement. Mulligan et al. (2012) also found that parents of children with ASD identified a need for support, information, and resources for navigating service utilization pathways.

Some central themes in the existing literature regarding service system limitations include: a need for public funding policies to support the development and dissemination of evidence-based practices for ASD; a need to provide mechanisms to evaluate the effectiveness of treatments in addressing individual and family goals; and a need to coordinate health care with educational and other services to improve health and education outcomes for children (Lord and Bishop, 2010; Peacock & Lin, 2012). Additionally, national best-practice recommendations need to be expanded to include early intervention, high fidelity and skilled staff, multiple and varied embedded learning opportunities, comprehensive curricula, functional approach to problem behavior, typically-developing peers, and family input (Strain, Schwartz, & Barton, 2011). Several of these best-practice recommendations would address challenges specifically identified by participants in this study, such as the need for funding, increased continuity of care, and more information regarding treatment options.

One example of how stakeholders can come together to provide insights to federal agencies about the process of advancing state-based collaborative efforts is the Act Early Initiative (Peacock & Lin, 2012). In 2008, regional summits were held in Kansas City, Missouri and Albuquerque, New Mexico, as a national attempt to address states' capacities to support the process of early identification and early intervention for children with ASD. At the summits, state representatives came together and created a list of recommendations regarding the process of advancing state-based collaborative efforts to be passed on to federal agencies. State representatives expressed a need for a comprehensive state-wide screening, identification, and referral system that can develop appropriate timelines for implementation of family-centered, culturally-competent

supports and services. State teams also emphasized a need for interdisciplinary training and professional development, specifically involving medicine, allied health, and education professionals. Lastly, state teams called for federal policies and funding to promote equal access to services across states and across all individuals with ASD (i.e., from different racial/ethnic groups and family income levels; Peacock & Lin, 2012).

Implications for research. Findings of the present study indicate future research should continue to explore the experience, function, and effects of empowerment among different demographic and geographic groups of caregivers of children with ASD. Specifically, collecting data using a longitudinal design may elicit helpful information for better understanding how caregivers' experiences of undergoing the processes of obtaining a diagnosis and accessing services may shift over time. Research that includes not only caregiver experiences but also the experiences of service providers (pediatricians, teachers, speech pathologists, occupational and behavioral therapists, etc.) would help to triangulate and add richness to the data. Lastly, translational research is needed to apply emerging research findings on facilitative factors to clinical and political settings.

Overall Contributions to the Literature

The present study sought to better understand the experiences of parents with ASD as they underwent the processes of obtaining a diagnosis and accessing services. While existing research has increasingly focused on examining these experiences, most studies focus on the experiences of white, middle-class families in metropolitan areas, whose experiences have been found to differ from those of traditionally underserved backgrounds (Nachshen & Minnes, 2005, Perry, 2013). The present study utilized

purposeful sampling in order to examine the experiences of parents from lower SES and ethnic minority backgrounds in the context of a largely rural state. This is the first study to focus on this population utilizing a transformative phenomenological methodology. The experiences of the parents in this unique sample closely parallel the experiences of parents in other studies in a number of ways, despite differences in SES and race/ethnicity. This is surprising given prior findings that low-income and ethnic minority families may face more challenges and barriers to early diagnosis and access to services compared to White/European American and higher income families (Liptak et al., 2008; Peacock & Lin, 2012; Thomas et al., 2007). It is possible that service utilization pathways are improving or have already improved significantly in the last few years. It is also possible there may be more service options and more equitable pathways to access available services in the geographic region from which data were collected compared to elsewhere in the United States. This is an important and hopeful finding of the current study, but it should be interpreted with caution and may be an area for further exploration in future studies.

Another important contribution to the existing literature is the emergence of *Constituent 8, fear regarding availability of future services and child's future after parents die*. While other studies have indicated this is an important theme for parents of adult children with DDs, the current study is the first to find that this is also a critical theme for parents of much younger, elementary school-aged children with ASD.

Another aim of the present study was to shed light on how parents from traditionally underserved groups (lower SES, ethnic minority) experience empowerment and advocacy with regards to diagnostic and service utilization pathways. This emphasis

on understanding empowerment and advocacy brings a focus on strengths to the study that is not always present in other research that highlights the negative experiences families face while obtaining an ASD diagnosis. Previous research has not focused enough on how caregivers adapt to the diagnosis, grow, and become stronger in the process of accessing services. This study illuminates what empowerment looks like among parents seeking a diagnosis and obtaining services. Results of the present study indicate that the experience of empowerment and engaging in advocacy have positive effects on parents, such as feeling more in control of their own and their families' lives.

Summary and Conclusion

Prevalence rates of ASD are increasing, currently affecting an estimated 1 in 68 children in the United States (Developmental, 2014). Compared to children with other specialized healthcare needs, children with ASD are underserved, with more delayed healthcare, less family-centered care, and more difficulties with referrals (Kogan et al., 2008; Lord & Bishop, 2010). Significant numbers of parents experience difficulties with the ASD diagnostic process and accessing available services (Goin-Kochel et al., 2006; Wiggins, Baio, & Rice, 2006). The available literature largely is focused on the experiences of middle to higher SES, urban, White parents of children with ASD.

This study illuminates the experience of the diagnostic and service utilization processes for six low income parents of children with ASD. This study contributes to a growing body of research about the experiences of parents with children with ASD. Unique contributions of this study include the finding of many similarities between the experiences reported by this low SES and ethnic minority sample and the prior findings with predominantly higher SES and White parents of children with ASD. Another unique

contribution was the emergence of fear regarding child's future after parents' death as a critical theme for parents of school-aged children. Lastly, this study brought a focus on strengths to an area of research that has not given enough attention to strengths-focused questions and methodology. As a result, this study found that caregivers can grow and become stronger in the process of accessing services for their child. Their identities as parents expand to include the role of expert on their child and advocate for their child, which is an empowering process for parents.

These findings have important implications for improving current diagnostic and service utilization pathways, and highlight the importance of facilitating parental empowerment, fostering shared decision making and collaborative relationships between parents and service providers, and addressing systemic challenges and barriers. This dissertation study demonstrates the complex multilevel systems that impact families' experiences going through these processes, and sheds light on the ways in which parents become stronger, more resilient, empowered advocates for their children.

APPENDIX A

OREGON EARLY AUTISM PROJECT WAVE II SELECTED MEASURES

TELEFORM: OE2DEMO

Oregon Early Autism Project: Demographics

DEMO (QB) Page 4 of 11

Research Compliance
Services
July 16, 2014
RECEIVED

Family ID:

Time: ● 2

A Little About You:

1. What is your name? _____
(first) (middle) (last)
2. What is your date of birth? / / Age:
(years)
3. What is your gender? Male Female
4. What is your race/ethnicity? (Check **all** that apply)
 - White/Caucasian
 - Black/African American
 - Hispanic/Latino
 - Asian
 - Native American
 - Pacific Islander
 - Other: _____
5. What is your place of birth? In the USA In another country: _____
6. What is your native language? _____ (language code)
7. Do you live with a spouse or partner? No Yes
8. Are you currently married? No Yes

The following are about your religious or spiritual beliefs

9. Do you have religious or spiritual beliefs? Yes No
 - a. How would you describe your religious or spiritual orientation?
 - Protestant Christian Other organized religion (specify): _____
 - Jewish Eastern (Buddhist or Hindu) Personal spiritual (unorganized) (specify): _____
 - Catholic Muslim _____
 - Mormon Jehovah's Witness _____
 - b. How important are these beliefs in your life?
 - Very important Important Somewhat important Slightly important Not at all important
 - c. In general, how often do you practice your religion or spirituality? For example, attending services, individual prayer, meditation, inspirational reading, or Bible study?
 - Daily Several times a week Weekly Less than weekly Holidays Not at all

Research
Compliance Services
Draft
07/16/2014 - 07/15/2015
"APPROVED"

Family ID: <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/> <input style="width: 20px; height: 20px;" type="text"/>	Time: ● 2
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The following questions are about your household income, your home, and financial stress

1. What is your annual household income: \$,

- a. \$4,999 or less
- b. \$5,000 to \$9,999
- c. \$10,000 to \$14,999
- d. \$15,000 to \$19,999
- e. \$20,000 to \$24,999
- f. \$25,000 to \$29,999
- g. \$30,000 to \$39,999
- h. \$40,000 to \$49,999
- i. \$50,000 to \$59,999
- j. \$60,000 to \$69,999
- k. \$70,000 to \$79,999
- l. \$80,000 to \$89,999
- m. \$90,000 or more

2. How much money does your family have?

- Not enough to get by
- Just enough to get by
- We only have to worry about money for fun or extras
- We never worry about money

3. How many children are you supporting?

4. Do you receive any of the following (*check all that apply*)?

- a. Temporary Assistance for Needy Families (TANF)/Welfare
- b. Social Security
- c. SSI (Supplemental Security Income)
- d. Medicaid
- e. Food Stamps
- f. Heating and Electric bill assistance
- g. Unemployment
- h. Child support
- i. Oregon Health Plan (OHP)
- j. WIC (Women, Infants, and Children)
- k. Food for Lane County
- l. Developmental Disability Services
- m. Tribal Insurance
- n. Respite Services

Family ID:

□ □ □ □ □ □ □ □

Time: ● 2

Directions: Below are a number of statements that describe how a parent or caregiver of a child with autism spectrum disorder may feel about his or her situation. For each statement, please fill in the circle that best describes how the statement applies to you.

	<u>Not True At All</u>	<u>Mostly Not True</u>	<u>Somewhat True</u>	<u>Mostly True</u>	<u>Very True</u>
1. I feel that I have a right to approve all services my child receives.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. When problems arise with my child, I handle them pretty well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. I feel I can have a part in improving services for children in my community.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. I feel confident in my ability to help my child grow and develop.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. I know the steps to take when I am concerned my child is receiving poor services.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. I make sure that professionals understand my opinions about what services my child needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. I know what to do when problems arise with my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. I get in touch with my legislators when important bills or issues concerning children are pending.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<u>Not True At All</u>	<u>Mostly Not True</u>	<u>Somewhat True</u>	<u>Mostly True</u>	<u>Very True</u>
9. I feel my family life is under control.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. I understand how the service system for children is organized.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
11. I am able to make good decisions about what services my child needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. I am able to work with agencies and professionals to decide what services my child needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. I make sure I stay in regular contact with professionals who are providing services to my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. I have ideas about the ideal services system for children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. I help other families get the services they need.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. I am able to get information to help me better understand my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Family ID:

Time: ● 2

	<u>Not True At All</u>	<u>Mostly Not True</u>	<u>Somewhat True</u>	<u>Mostly True</u>	<u>Very True</u>
17. I believe that other parents and I can have an influence on services for children.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. My opinion is just as important as professionals' opinions in deciding what services my child needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. I tell professionals what I think about services being provided to my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. I tell people in agencies and government how services for children can be improved.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
21. I believe I can solve problems with my child when they happen.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
22. I know how to get agency administrators or legislators to listen to me.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
23. I know what services my child needs.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
24. I know what the rights of parents and children are under the special education laws.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
	<u>Not True At All</u>	<u>Mostly Not True</u>	<u>Somewhat True</u>	<u>Mostly True</u>	<u>Very True</u>
25. I feel that my knowledge and experience as a parent can be used to improve services for children and families.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
26. When I need help with problems in my family, I am able to ask for help from others.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
27. I make efforts to learn new ways to help my child grow and develop.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
28. When necessary, I take the initiative in looking for services for my child and family.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
29. When dealing with my child, I focus on the good things as well as the problems.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
30. I have a good understanding of the service system that my child is involved in.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
31. When faced with a problem involving my child, I decide what to do and then do it.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
32. Professionals should ask me what services I want for my child.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
33. I have a good understanding of my child's disorder.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
34. I feel I am a good parent.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

APPENDIX B

UNIVERSITY OF OREGON INSTITUTIONAL REVIEW BOARD APPROVAL



UNIVERSITY OF OREGON

DATE: May 15, 2015 IRB Protocol Number: 03312015.033

TO: Nina Hidalgo, Principal Investigator Department of Family and Human Services

RE: Protocol entitled, “A Phenomenological Exploration of Parents? Psychological Experiences Obtaining a Diagnosis and Access to Services for Their Children with Autism Spectrum Disorder”

Notice of IRB Review and Approval Expedited Review as per Title 45 CFR Part 46 # 6, 7

The project identified above has been reviewed by the University of Oregon Institutional Review Board (IRB) and Research Compliance Services using an expedited review procedure. This is a minimal risk study. This approval is based on the assumption that the materials, including changes/clarifications that you submitted to the IRB contain a complete and accurate description of all the ways in which human subjects are involved in your research.

For this research, the following additional determinations have been made: · The IRB has waived the requirement to obtain assent from children under 45 CFR 46.116(d) who will serve as secondary subjects in the research. Adequate provisions for obtaining consent and parental permission are in place.

NOTE: This approval is contingent upon the submission and IRB approval of an amendment to Laura McIntyre’s protocol, Early Autism Project (“OEAP”, RCS #08212011.072) that explains the recruitment process to be used in this study.

This approval is given with the following standard conditions:

- . You are approved to conduct this research only during the period of approval cited below;
- . You will conduct the research according to the plans and protocol submitted (approved copy enclosed);
- . You will immediately inform Research Compliance Services of any injuries or adverse research events involving subjects;
- . You will immediately request approval from the IRB of any proposed changes in your research, and you will not initiate any changes until they have been reviewed and approved by the IRB;

- . You will only use the approved informed consent document(s) (enclosed);
- . You will give each research subject a copy of the informed consent document;
- . If your research is anticipated to continue beyond the IRB approval dates, you must submit a Continuing Review Request to the IRB approximately 60 days prior to IRB approval expiration date. Without continuing approval the Protocol will automatically expire on May 14, 2016.

Additional Conditions: Any research personnel that have not completed CITI certificates should be removed from the project until they have completed the training. When they have completed the training, you must submit a Protocol Amendment Application Form to add their names to the protocol, along with a copy of their CITI certificates.

Approval period: May 15, 2015 - May 14, 2016

The University of Oregon and Research Compliance Services appreciate your efforts to conduct research in compliance with University of Oregon Policy and federal regulations that have been established to ensure the protection of human subjects in research. Thank you for your cooperation with the IRB process.

Sincerely,

Carolyn J. Craig, Ph.D. Research Compliance Administrator
CC: Laura McIntyre, Faculty Advisor Angela Relling, Research Assistant

APPENDIX C

RECRUITMENT MATERIALS

Phone Screen and Scheduling Form

Hello, my name is Nina Hidalgo from the University of Oregon. I'm calling you today because you completed an interview for (insert child's name) a couple of [months/weeks] ago for the Oregon Early Autism Project being conducted by Dr. Laura Lee McIntyre and team of researchers, including myself, from the Child and Family Center and the College of Education. You completed a mail home packet of questionnaires, a phone interview, and an in-home interview. We asked you questions about (insert child's name) Autism Spectrum Disorder diagnosis and services, and also questions about your family. We have completed that piece of the project and I am calling you today to invite you to do some follow-up interviews for the Family Experiences Project with me. I would like to see if you might be eligible to participate, and if so, I would like to give you some more information to see if you might be interested in participating. Is this a good time to talk? (If not, when would be a better time?).

Great, before I read the description of the project, does (child's name) still live with you? Has (child's name) always lived with you since he/she received their diagnosis or qualified for special education services for Autism Spectrum Disorder?

*If No on either question say: Unfortunately, to complete some of our questions, (child's name) needs to be living with you uninterrupted since their diagnosis or eligibility. Thank you for your continued interest in our project. Have a good day!

*If Yes, Continue:

This is a study funded by the College of Education at the University of Oregon. I am the principal investigator. I am doctoral candidate in the counseling psychology program at the University of Oregon. I am interested in parents' experiences going through the diagnostic and service utilization processes for their children who have been diagnosed with or have received special education services for an autism spectrum disorder.

I am contacting families that completed both of the Oregon Early Autism Project interviews and inviting them to participate in my study. This study consists of two at-home (or wherever you might prefer) interviews. I will be asking you questions about your child, your family, and your experiences obtaining a diagnosis and accessing services for your child. Your child does not need to be present during the interview. Each interview should take approximately 60-90 minutes. I will compensate you \$40 for your time at the end of the second interview.

Participation in this study is voluntary, so you can choose to participate or not. Additionally, everything that we talk about is confidential. This means that we cannot disclose what you've shared with us. We can't share what you've discussed with us with

your child's teachers, service coordinators, therapists, or doctors. Your confidentiality is protected. Should you decide to participate in the study, I will go over an Informed Consent Form which describes everything in more detail. I'll also make sure that you get a chance to have any of your questions answered.

The findings from our study will be summarized and will be available to families who participate in the project, as well as professionals in the field. I will remove all identifying information from the results so individual families will not be identified.

Do you have questions at this time?

Would you like to participate in this project?

*If No say: Thank you for your time and if you have any questions, please feel free to call me. Have good day!

*If Yes say: Great! I would like to make sure I have correct information and then I can schedule you for your home visit.

- - - - -

(Only complete if eligible and caregiver wishes to participate in interview)

Caregiver's Name:

Phone #: (Home) _____
(Work) _____

Cell# or Other: _____
Email _____

Home Address:

Mailing Address: (if different)

Interview 1 Scheduled:

Day _____ **Date** _____ / _____ / _____

Time: _____

Special Instructions?

Location if not in home:

Interview 2 Scheduled:

Day _____ **Date** ____ / ____ / ____

Time: _____

Special Instructions?

Location if not in home_

University of Oregon
College of Education

Investigator: Nina Hidalgo, M.S.

Faculty Research Supervisor: Laura Lee McIntyre, Ph.D.

Adult Consent Form

Introduction

- You are being asked to complete two interviews for caregivers who have a child with an autism spectrum disorder (ASD).
- You are being invited to participate in this project because you participated in the Wave 2 interview for the Oregon Early Autism Project.
- We ask that you read this form and ask any questions that you may have before agreeing to be in the study.

Purpose of Study:

- The purpose of this study is to better understand how families experience the process of a diagnosis and accessing services for their child with ASD. **This study is being done for research purposes only.**
- We will be inviting 10 caregivers to participate in these interviews.

Description of the Study Procedures:

- This study consists of two 90-minute interviews in your home or another location of your choice. . During the interviews we will ask you some questions about your experiences with different types of services and about the steps you took to get a diagnosis for your child with ASD.
- Both interviews will be audio recorded.. The audio recording is required for participation in this study.
- The total completion time for this study will be about 3 hours (two 90 min interviews). You will be paid \$40 to compensate you for your time at the end of the second interview.

Risks/Discomforts of Being in the Study:

- Potential risks are minimal and include possible psychological or emotional risks and information risks involving breach of confidentiality.
 - **Psychological or emotional risk.** You may feel some discomfort answering questions that ask about your child's development and

difficulties you may have faced interacting with medical and service systems for your child with ASD. Some participants may view the home interviews as minimally intrusive.

- **Breach of confidentiality.** Although project staff members go to great lengths to protect your confidentiality, there is a small risk that your name may be associated with your study participation. We minimize the risk of breach of confidentiality by coding all information you provide during the home visit so that it cannot be associated with any individual or family. Identifying information needed for participant contact, such as names, addresses, and telephone numbers, will be kept in locked file cabinets in locked offices. Only designated project staff will have access to this information. Audio recordings will be destroyed after the interviews are transcribed, and identifying information will be removed and/or coded during transcription.

Benefits of Being in the Study:

- The purpose of this study is to better understand how families experience the steps they take in obtaining a diagnosis and accessing services for their child with ASD.
- The benefits of participation may include: psychological or emotional benefits, learning benefits, and benefits to the scientific community.
 - **Psychological benefits.** You may find it interesting and rewarding to contribute to scientific research and advance knowledge about diagnostic and service utilization pathways for children with ASD and their families.
 - **Learning benefits.** Parents who participate in this interview will be given a summary of what other families who are participating are experiencing.
 - **Benefits to the scientific community.** Knowledge gained from this study may assist in the development of more effective, family-friendly supports to promote positive child and family outcomes in families with children with an ASD diagnosis.

Costs:

- There is no cost to you to participate in this research study.

Confidentiality:

- The records of this study will be kept private. When we publish in papers or journals we do not include any identifiable information. Research records will be kept in a locked file.
- All electronic information will be coded and secured using a password protected file and a secure server.
- Access to the records will be limited to the researchers; however, please note that the Institutional Review Board and internal University of Oregon auditors may review the research records.

- Under Oregon state law, research staff are required to report suspected or known abuse of children or elderly individuals, or if an individual discloses an intent to harm him/herself or others. If any member of the research staff has or is given such information, we are required to report it to authorities.

Voluntary Participation/Withdrawal:

- Your participation is voluntary. If you choose not to participate, it will not affect your current or future relations with the University of Oregon.
- You are free to withdraw at any time, for whatever reason.
- There is no penalty or loss of benefits for not taking part or for stopping your participation.
- **You do not have to answer any question that you do not want to answer.**

Contacts and Questions:

- The researcher conducting this study is Nina Hidalgo. For questions of more information concerning this research, you may contact her at (650-218-5596) or nina@uoregon.edu (e-mail)
- The faculty research supervisor for this study is Laura Lee McIntyre, PhD. For questions or more information concerning this research, or if you believe you may have suffered a research related injury, you may contact her at (541-346-5123) or llmcinty@uoregon.edu (e-mail).
- If you have any questions about your rights as a research subject, you may contact: the Research Compliance Services Office, University of Oregon at (541-346-2510) or ResearchCompliance@uoregon.edu (e-mail)

Copy of Consent Form:

- You will be given a copy of this form to keep for your records and future reference.

Statement of Consent:

- I have read (or have had read to me) the contents of this consent form and have been encouraged to ask questions. I have received answers to my questions. I give my consent to participate in this project. I have received (or will receive) a copy of this form.

Signatures/Dates

Printed Name of Primary Caregiver _____

Relationship to Child _____

Primary Caregiver Signature _____

Date _____

Verification of Explanation:

I certify that I have carefully explained the purpose and nature of this research to:
_____ in appropriate language. She/he has had an opportunity to discuss
it with me in detail. I have answered all her/his questions and she/he provided affirmative
agreement to participate in this research study.

Researcher's Signature _____

Date _____

APPENDIX D

PROTOCOLS AND INTERVIEW MATERIALS

University of Oregon
College of Education

Family Experiences Project

Investigator: Nina Hidalgo, M.S.
Faculty Research Supervisor: Laura Lee McIntyre, Ph.D.

Interview #1

- Tell me a little bit about your child, _____.
 - What does _____ enjoy doing?
 - What was _____ like as an infant?

- How and when did you first find out that your child had autism?
 - What came first, diagnosis or services?
 - What was the experience of going through that first process (Dx or accessing services)?
 - Can you tell me more about _____? Exactly what happened? Please be as specific and detailed as you can.
 - How has this experience affected you/your family's life? What kind of impact has it had on you/your family's life?
 - What was the experience of going through that second process (Dx or accessing services)?
 - Can you tell me more about _____? Exactly what happened? Please be as specific and detailed as you can.
 - How has this experience affected you/your family's life? What kind of impact has it had on you/your family's life?

- What kind of problems or barriers have you faced when trying to get services for _____?
 - How have you dealt with these issues?
 - Who/what else has been helpful in the process?
 - How have these experiences affected you/your family's life? What kind of impact has it had on you/your family's life?

- Do you remember a time when you had to really push the system (or advocate) to get services needed for your child?
 - What happened? Please be as specific and detailed as you can.
 - What did you learn through that experience?

- How has this experience affected your/your family's life? What kind of impact has it had on your/your family's life?
- What services or supports are working really well for your child/family?
 - How did you get connected to those services?
- Do you have anything else you want to tell me?

Interview #2 **Date:** _____

Intro: You're the expert on your experience; I'm here because I want to hear about them from you, with as much detail and specificity as you can. I may nudge or press for more detail here and there, but please remember it's ok if you don't remember, and it's ok to say no or ask me to move on to the next question.

- Thinking back to the process of diagnosis and getting services, what it did feel like to go through the diagnostic process?
 - What went through your mind?
 - What/who has been helpful in this process, if anything?

- In our last meetings, I asked you about what services are working well for your family, what about these services, specifically, makes them helpful/positive experiences?
 - What about the staff/service providers, if anything, contributes to the positive/helpful experiences receiving these services?

- We talked a bit about community/social support in our last meeting, can you say more about what/who makes up you community/social support system?
 - Where/how did you find it?
 - What impact does it have on you/your family's life?
 - What, if anything, might be lacking? Unmet needs? What's missing?

- Based on your experiences that we've discussed in our previous meeting (summarize), what have you learned?
 - About navigating the diagnostic process?
 - About accessing services?
 - About dealing with challenges/barriers?

- What would you tell another parent who just found out that their child had a diagnosis of autism?
 - Do you have any specific recommendations?

- Do you have anything else you want to tell me?

University of Oregon
College of Education

Family Experiences Project

Investigator: Nina Hidalgo, M.S.
Faculty Research Supervisor: Laura Lee McIntyre, Ph.D.

Honorarium Form

By signing below, I certify that I have received \$40 in cash from Nina Hidalgo as an honorarium for participating in the Family Experiences Project.

Printed Name of Primary Caregiver

Primary Caregiver Signature

Date

Printed Name of Primary Investigator

Primary Investigator Signature

Date

APPENDIX E
PARTICIPANT SUMMARY AND INVITATION FOR FEEDBACK



Hello!

Thank you again for your participation in my study. Please find a brief, 3-page summary of the study and findings attached to this letter for your review. Feel free to contact me by phone at **(650) 218-5596** or by email at **nina@uoregon.edu** if you have any questions, comments, or feedback. Should you have any requested edits to the findings, please do try to contact me by 3/25/16 so that I can have sufficient time to make changes to the final document. And lastly, if you would like a copy of the complete dissertation study, let me know and I will make sure to send a copy in June once it is finished.

Thanks again,

Nina Hidalgo, MS

Graduate Teaching Fellow, Family & Human Services

Doctoral Candidate, Counseling Psychology

University of Oregon



Family Experiences with ASD Diagnosis and Service Utilization

Introduction and Background:

Autism spectrum disorders (ASD) are the fastest growing group of neurodevelopmental disorders in childhood, affecting an estimated 1 in 68 children in the United States (Developmental, 2014). Compared to children with other specialized healthcare needs, children with ASD are underserved, with more delayed healthcare, less family-centered care, and more difficulties with referrals (Kogan et al., 2008; Lord & Bishop, 2010). Families of children with ASD have more financial problems, provide more than 10 hours a week of healthcare coordination for their children, and are more likely to stop or reduce work than families of other groups of children with special needs (Honberg, Kogan, Allen, Strickland, & Newacheck, 2009; Kogan, et al., 2008; Lord & Bishop, 2010).

Research indicates that significant numbers of parents experience difficulties with the ASD diagnostic process and accessing available services (Goin-Kochel et al., 2006; Wiggins, Baio, & Rice, 2006). Many parents report negative experiences as they seek a diagnosis, including long wait times, feeling disrespected, isolated, confused, and frustrated with current diagnostic and service utilization pathways (Ahern, 2000; Mulligan, MacCulloch, Good, & Nicholas, 2012; Schall, 2000). There is a lack of research designed to explore and understand the psychological experiences of parents going through these processes. This information is crucial to affecting systemic change that results in more supportive diagnostic and service utilization pathways for these families.

Purpose of the Study:

The purpose of this research was to acquire knowledge of parents' psychological experiences obtaining a diagnosis and accessing services for their child with ASD by examining the actual situation, as lived through and experienced by the parents; gain knowledge of the meaning of advocacy and empowerment from parents who are having these experiences; and analyze the parent experiences and determine if these may have implications that could affect services provided by mental health professionals, service providers, and policy-makers.

Steps:

Six parents and caregivers of children with a previous or current diagnosis for Autism Spectrum Disorder (ASD) that had participated in the Oregon Early Autism Project (Early Autism Project; PI, McIntyre) participated in two, 60-90 minute interviews.

Interviews were conducted in the participants' homes, or at another participant-preferred location. Parents were asked about their experiences in relation to their child's diagnosis, accessing services, satisfaction with services, and their relationships.

Findings:

What are parents' experiences going through the diagnostic and service utilization process for their child with ASD?

Themes:

1. Uncertainty regarding what a diagnosis of ASD means and what will happen next in regards to child functioning and services.
2. Increased access to services and information regarding ASD and available services following a diagnosis.
3. Relational strain and frustration with people in social support network that misunderstand ASD and/or judge parent for their child's ASD behavior.
4. Awareness of challenges, barriers, and limitations in the service access and utilization process, leading to frustration and some distrust in service systems and service providers.
5. A desire and/or appreciation for sources of support and information regarding services: collaborative, strengths-based service providers and communities of other parents of children with special needs.
6. Engagement in ongoing research and networking to learn about available services and pathways to utilization.
7. A need to be the expert on their child in order to communicate clearly with professionals regarding their child's unique needs and to determine which services are worth pursuing.
8. Fear regarding availability of future services and child's future after parents die.

Quotes:

"I have learned that if you don't know what's out there, the people providing the service are not necessarily going to tell you. They are not doing it on purpose. I think they are overworked, they are overwhelmed... I think unfortunately you are not going to be told everything and sometimes you'll find out a year or two later that they provide something you didn't even know about. Those were the kind of bummers, like I could have been doing this a year or two ago. I think that it's just built in the system unfortunately.... I think I still have a little anger about stuff. I try not to be angry. But it comes out with the feeling of, "Why is it so hard to do this?" It's very hard when you are already using a lot of your energy to figure out what your child needs, get that taken care of, the next thing. Then over here I still have to figure out how to talk to [service providers]. So, that can get frustrating."

"I just really appreciated that understanding and just the understanding and the patience and me answering questions and again trying to be that mama that wants to showcase what he can do and like all the good things and being able to ask the hard questions in a gentle way and help me understand this is hard, but it's going to help us know how to help your son. That was so good and so different than what we had experienced before."

What is the psychological meaning of empowerment for parents' experiences going through the diagnostic and service utilization process for their child with ASD?

Themes:

1. Awareness of the limitations of service systems and relevant power dynamics affecting service access and utilization.
2. Seeing self as expert on child.
3. Persistence in obtaining access to services and accommodations.
4. Engagement in research to stay informed about ASD, services, and systems involved.
5. Sharing knowledge with other parents/the ASD community.

Quotes:

“Just because you are an educator does not mean you are always right. Here I thought like you are going to college, you know more than I do. I could not know as much as you know. I don't know as much as they know, but I know what's right for my child. Ultimately that's okay and whether they see it today, they might see it tomorrow, so I have to keep chugging along and believing in my child, because I know someday that he will be successful I just have to get him there, so I'm chugging on.”

“I will say you have to be persistent. You have to push a lot, and if you are not used to that it's hard. Like I got used to it...I realized okay, I have to be pushy. I have to regularly, I hear from parents, who say, “Oh my God, [Developmental Disability Services] took 6 months.” There is no way I'm going to let it take 6 months. I showed up at the door, I would call regularly. If I didn't get one of them I would show up, I would be like, “Can I see the supervisor?” So, if you don't do that, you can get lost in the system. You have to keep pushing. I don't blame [the caseworkers] as much, I know they are overtaxed. It's so much need, not enough people, not enough resources. But I feel like if you don't push you are not going to get what you need. So, in that way you are always pushing too as a mom, or as a parent.”

What is the psychological meaning of advocacy for parents' experiences going through the diagnostic and service utilization process for their child with ASD?

Themes:

1. Seeing self as expert on child with an active role in the service utilization process
2. Educating/engaging community members regarding advocacy efforts.

Quotes:

“I think that for me, turning outwards to all these other moms has made it better for me and helping to start the A Team has made it better for me too. Like, I don't feel that feeling of like, I don't feel, “Oh this is me, this is so hard.” I feel more like, “What are we going to do here and how do we band together and make ourselves heard?” because the reality is it's always parents. Mental institutions, they close down for parents, Mothers against Drunk Driving. I feel like it's often parents who say, “We are tired of this.” I feel like that's still going to have to keep happening and we are going to I think, there are still things that I see that are

messed up. But for me I don't feel lost. I feel more like, I think I feel empowered by what we have chosen to do. There is no other word."

"You are also teaching people, as I do with [my child], teaching people to advocate for themselves. If this isn't working try something else. Ask another person. Ask 7 other people. I've been doing that with [my child], and I have been encouraging him to ask for what he wants, 'If this isn't working for you, you need to tell people how it can.'"

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