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# Eleven case studies of parents' experiences when accessing services for an Autistic Spectrum Disorder child

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# ELEVEN CASE STUDIES OF PARENTS' EXPERIENCES WHEN ACCESSING SERVICES FOR AN AUTISTIC SPECTRUM DISORDER CHILD

A Project
Presented to the
Faculty of
California State University,
San Bernardino

In Partial Fulfillment
of the Requirements for the Degree
Master of Social Work

by
Barbara Michelle Wood
June 2010

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# ABSTRACT

Autism Spectrum Disorder's (ASD) prevalence rates are steadily increasing; 1-91 children are diagnosed each year (Kogan et al., 2009). The future success of these children and their families relies heavily on their ability to access a variety of necessary therapies. Literature shows that parents struggle to access the necessary resources to treat ASD. This research project engaged 11 families in in-depth interviews exploring their experiences accessing services. Four areas of services emerged from the interviews and they were, diagnostic services , services through Regional Centers, services offered at their child's school, and other services accessed (i.e. through insurance or community organizations). Parents who educated themselves about the services available to them tend to access more services. Most parents involved in the study were looking for more services available to their ASD children in their communities that would increase their children's social skills. Social Workers play an invaluable role in parents accessing services for their ASD children, particularly in the role of advocate.

# ACKNOWLEDGMENTS

To God without whom this accomplishment would not be possible. Jordan and Aidan my love for you is endless. Mom and Dean, you are instrumental in my life and I love you both for all of your endless support. Tiffany, Summer, Durinda, Robin, Natalie, Bug, and Myrna, you are each a dear friend to me and I appreciate your ability to distract and support me. Dr. Morris all of the time and energy you put into making this project happen successfully is greatly appreciated. Timothy Thelander thank you for your guidance and friendship over the years. To each of my supervisors, Nick Watson, Eileen Watson, and Anne Sims, Thank you for sharing your knowledge and experience with me. The opportunity I had with each of as my supervisor is invaluable. To my extended family, just in case you read this, I love you all in a unique way.

# DEDICATION

Jordan and Aidan- Without you this project would not have been planted.

Mommacita- Without you this project would not have bloomed.

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# CHAPTER ONE

# ASSESSMENT

## Introduction

Autism Spectrum Disorder's (ASD) prevalence rates are steadily increasing; 1-91 children are diagnosed each year (Kogan et al., 2009) with no reprieve in sight and little understanding of its cause. The future success of these children and their families rely heavily on their ability to access a variety of necessary therapies. Literature shows that parents are stressed and struggling to access the necessary resources to treat ASD (Grecco, Sloper, Webb, & Beecham, 2007; Twoy, Connolly, & Novak, 2006; Osborne, McHugh, Saunders, & Reed, 2008). This project took an in depth look at parent's experience accessing resources for their ASD children.

## Problem Statement

The prevalence rate of children with Autism Spectrum Disorder (ASD) has risen to one percent of all United States children, which means that approximately 1 in 91 children between the ages of 3-17 have been or will be diagnosed with ASD (Kogan et al., 2009). The 19th edition of the Social Work Encyclopedia cited that prevalence rates were as low as 1 in every 2000 children being diagnosed with ASD in 2007 (DeWeaver, 1995). For the Social Work Profession to effectively assess and meet the needs of the increasing number of families raising an ASD child, we have to first start where the client is and work to understand the family's needs, goals, history, and abilities.

While millions of families are affected each year by ASD, many people and professionals are unfamiliar with the plight families living with ASD are facing. Suzanne Wright, founder of Autism Speaks and mother of an ASD child, wrote in an article entitled *Willing the World to Listen*, "that there is a gap in both awareness and services for families with ASD children to access" (2005, p. 47). Further reducing the ability for families to access immediate and appropriate services is the cost for necessary, scarce, treatments and services.

> Autism Society estimated that the lifetime cost of caring for a child with autism ranges from $3.5 million to $5 million, and that the United States is facing almost $90 billion annually in costs for autism (this figure includes research, insurance costs and non-covered expenses, Medicaid waivers for

> autism, educational spending, housing, transportation, employment, in addition to related therapeutic services and caregiver costs). (Autism Society of America, 2010, para. 3)

As unique as each child is with ASD, his or her family's choice in services and ability to access service is equally unique. For this reason there is no "cookie cutter" parenting manual handed to parents when their child is diagnosed on what services are the best for their child's special needs or the best way to access those services. In order for a parent to immerse an ASD child into a successful treatment plan, the family must first recognize their child's individual and unique needs and be open to a broad array of treatments (Thomas, Ellis, McLaurin, Daniels, & Morrissey, 2007). Parents have to network with the other families in the Autism community, gather medical professional's suggestions/referrals and do self-initiating research on services that can be beneficial and are available in their service area to ensure that their children are receiving all the appropriate services.

Bernard Rimland Ph.D., and father of an ASD child, formed the Autism Society of America in 1965 with the mission of involving the ASD person and family in advocating for and connecting to services that are appropriate, supportive, and individualized. While legislation exists that benefits the developmentally delayed in accessing services, like the Lanterman Developmental Services Act (State of California Department of Developmental Services, 1969) which created agencies such as the Inland Regional Centers that provide comprehensive case management to developmentally disabled peoples in California, a gap remains between the needed services an ASD child needs and what he or she is receiving.

Policies guiding autism research and services have begun to evolve as needs and demands have increased. In 2001 the American Academy of Pediatrics changed their policy on screening for and treating ASD by recommending that every child be screened for ASD twice before the age of two and concurrently recommending that treatment services begin at the suspicion of ASD and not when the "formal" diagnosis is made (Johnson, Meyers, & the Council on Children with Disabilities, 2007).

There are many celebrities who speak about how ASD has affected their families; Joe Montana, Tony Braxton, and Jenny McCarthy are a few. While celebrities' support has encouraged donations of millions of dollars for research funding and exposure to ASD, their stories of utilizing pricey therapies at their convenience are a striking contrast with those of families struggling to receive resources locally.

In order for the tide to change and families living with ASD to gain headway in their path for understanding and accessing resources, we, as Social Workers, have to first listen to their experiences. As Social Workers we have to collect information about their strengths, success, failures, struggles, and aspirations for their ASD children to gain understanding and empathy. Under the National Association of Social Work (NASW) code of ethics there are six ethical principles and values all social workers are held to. These values are that of; service, social justice, dignity and worth of the person, importance of human relationships, integrity, and competence (1996). Social Workers have an obligation to hear to the voices of parents raising ASD children and to direct attention to the adversity these families are facing based on each of the six values we as Social Workers are held to.

# Purpose of the Study

The purpose of this study is to understand parents' experience of accessing services for their ASD children. It was this research's goal to document parent's stories and experiences of accessing services for their ASD children. The study's findings will guide future Social Work practice and assist in better engagement and servicing of this population.

# Literature Review

## Introduction

A comprehensive Literature Review was carried out to develop the problem statement for this study. The review focused on two themes in the literature; parent's experience of ASD, and parents experience with receiving services for their ASD children.

## Parent's Experience of Autism Spectrum Disorder

In this section of the literature, this researcher looked at what society has historically thought of parents raising ASD children and then evolves into looking at what the research is currently focused on. While researching the current trends in research two themes evolved. One theme was that parents raising ASD children are under tremendous stress (Grecco et al., 2007; Twoy et al., 2006; Osborne et al., 2008) and the second theme was that parents raising ASD children feel isolated from the world (Woodgate & Ateah, 2008).

## Current Research Focus

In 1964 the dominating belief in society was that the mother of an ASD child suffered from a psychological disorder and both the mother and child could benefit from psychotherapy (Rimland, 2003). While ASD is no longer viewed as a product of a mother's psychological disorder, research detailing experiences of ASD people, often leaves out the experiences of their parents experience raising an ASD child. Often ASD leaves children and adults without language or the ability to express emotions. So of course, researchers and society are intrigued when we can get a glimpse into "their world."

Several articles identified a gap in the literature. Typically researchers have focused on the impact a particular service has on family dynamics and not taken advantage of the opportunity to gain knowledge through documenting the parent's experience (Webster, Feiler, Webster, & Lovell, 2004). Two separate articles identified a more specific gap in the research, and that was studying mothers of special needs children. Levine (2009) describes the dedication and determination, single mothers in particular, encompass when seeking and receiving services for their special needs child (2009). The article notes that single mothers prove to be more resilient and try to challenge the notion that they might be unable to care for a special needs child. Studies of this phenomenon have received minimal attention. Leiter et al., (2004) explored the hardships women as mothers of disabled children face in their family networks and in the work force and the little research that has been done to identify strengths and needs in this cohort (2004).

Looking more closely at parent's experience with ASD, as documented in research, two themes appeared. One was that stress is particularly high among parents who are raising ASD children (Grecco et al., 2007; Twoy et al., 2006; Osborne et al., 2008). And the second theme was that parent's have reported feeling isolated from the world around them (Woodgate & Ateah, 2008).

### Stress

Parents who are raising ASD children are experiencing a particularly high amount of stress (Grecco et al., 2007; Twoy et al., 2006; Osborne et al., 2008).

Despite these high stress levels, parents are more likely to access services because their stress levels are high (Thomas et al., 2007). A reason that parents access service when stress levels are high is that the burden remains solely with the parents for providing care for a special needs child, as well, often it is the child's "more difficult temperaments" that parents seek services for (Iscoe, & Bordelon, 1985; Rivers, & Stoneman, 2008, p. 1741). In particular caring for a special needs child demands a parent to gain "specialized knowledge," and collaborate effectively with professionals in order to gain that knowledge and provide specialized care to their child (Leiter, Krauss, Anderson, & Wells, 2004, p. 382).

The literature suggested that the role of the social worker in reducing stress in this population should be aiding parents of ASD children in accessing needed services. In particular research done in England and Wales looked at the effect "key workers" had on reducing stress in parents raising ASD children (Grecco et al., 2007). A key worker is a model that could be used in the United States. The Key worker assesses the needs of the family, coordinates services for that family, and collaborates with other agencies to ensure a tailored service for that family (Grecco et al., 2007). Key workers who have been thoroughly and properly educated have been shown to greatly reduce the stress of parent's with an ASD child by allowing the mother to focus on the child rather than searching out services and by providing service like respite care to allow for a "break" for the parents (Grecco et al., 2007).

Another way parents have reduced their stress is to utilize their family system as discovered by Twoy et al. Twoy et al. surveyed parents of ASD children using the Family Crisis Oriented Personal Evaluation Scales, which looks at a families ability to cope and use of resiliency (2006). The two themes that emerged through the research were identified as seeking encouragement and support through extended family, formal support and support groups, informal support (Twoy et al., 2006). Further the research described that formal support systems assist in relieving stress by "providing positive feedback" to the parents of ASD children (Twoy et al., 2006, p. 258). Support groups were shown to support parents and relieve the stress of ASD children by providing education on their child's educational rights (Twoy et al., 2006).

## Isolation

Parents have reported that like their children who are often described as "being in their own world," they too often feel isolated (Woodgate & Ateah, 2008). Woodgate and Ateah (2008) describes the circumstances that lead a parent to feeling isolated as; 1.) society not understanding their children's peculiar behaviors and the stigmatization that came from the lack of societies understanding, 2.) parent's are missing out on typical child rearing experiences spending more time accessing services for their children than time spent doing traditional bonding activities (i.e. going to the park), 3.) disengaging from their family when there is lack of understanding or being on different pages about treatment options, both from the extended family and spouses, and 4.) the "system" does not support their children's needs, making services inaccessible and unsupportive, therefore it isolates them further.

The literature revealed helpful themes that may not apply to all parents but that guided the direction this researcher took in doing research in the field. The themes that emerged are that parents with ASD children are susceptible to stress and isolation.

## Parents Experience with Accessing Services for their Autism Spectrum Disorder Children

The literature shows that parents often struggle with accessing the appropriate services their ASD children may require (Woodgate & Ateah, 2008). This section of the literature review explores parents' experience of accessing services for their ASD children.

"There is a wide range of educational and therapy options for ASD, emanating from different theoretical perspectives, all of which lay claim to some success for some children" (Webster et al., 2004, p. 26). Understanding the vast array of options a parent has to consider in seeking services for their children can lay the foundation for understanding how complicated and difficult it might be for a parent to first choose what type of services are appropriate to access and then managing how to access those services. There are educational/behavioral approaches to consider, Applied Behavior Analysis (ABA), Sensory Integration therapies, medical interventions, diets, Speech Therapy, Occupational Therapy, Physical Therapy, and Auditory approaches. All of the above are interventions that an ASD child should be assessed and considered for when choosing services for the benefit of an ASD child (Adams, Edelson, Grandin, & Rimland, 2008). All these treatments can be very expensive, time consuming, and hard to access.

A study conducted in Northern California stated that parents were satisfied with the services offered by their local educational system, and the Northern California Regional Center (Drummer, 2007). There were several articles; however, countering those findings that claimed parent's are unsatisfied with the accessibility of services for their ASD children. For example, Woodgate and Ateah (2008) reported that not only were services inaccessible, but that the professionals were unsupportive and lacked training and as a result parents felt defeated.

## Summary

In summary the literature is limited on detailing the experience parents have trying to access service for their ASD children. The literature also recognized that the role of the "key worker" benefits the functioning of the family by relieving stress, isolation and in facilitating the accessing of services. Through this literature review, it is evident that the purposed study adds to the body of literature that is available and gives a voice to parent's raising ASD children.

## Theoretical Orientation

### Empowerment

To empower a disadvantaged population is to give that population the key to their future. *Theories of Social Work Practice*, describes the empowerment theory as a way to address social inequality, to become aware of the opposing force; accept responsibility and engage in action through gaining access to resources and determine their own destiny (Lary, 2005). The belief that through empowerment you can rise above your oppression has been a theme throughout social work history.

While empowerment is an important part of an intervention, it has been underappreciated and can be viewed as deceptively complex by Social Workers (Cagle & Kovacs, 2009). Social Workers by nature are charged with empowering the oppressed, and vulnerable to encourage self-determination, prevent crisis and to do this in a culturally sensitive and empowering way (Cagle & Kovacs, 2009).

Empowerment is the key to the success of parenting an ASD child and accessing the services. Without a feeling of empowerment it would be easy for a parent to be passive to their child's needs. Once a parent is empowered to seek a solution a parent can achieve anything for that child. Empowerment will allow a parent to decide their child's future in all aspects of the course they go on with an ASD child.

This study aimed to empower parents by giving them a voice and a chance to reflect on their own experience raising an ASD child. The founders of "Autism Speaks", Suzanne Wright, and Autism Society of America, Berlin Rimland found the system to lack the necessary support for their ASD child and empowered themselves to become activists in the community challenging society to hear their stories. However, not every family raising an ASD child has the ability or knowledge to create a forum where their voices and knowledge can be shared. For some of those parents this research was an opportunity to share their experience, empowering them to continue on their journey and seek more information, educating themselves on the available services.

## Significance of Project for Social Work Practice

### Introduction

When engaging any client, we as Social Workers have a duty to be knowledgeable about the population we are serving. In order to be knowledgeable social work relies on research to inform us about specific topics. The research this study is conducting is starting with the client to understand what their concern is and how the Social Work profession can increase their knowledge and awareness about the experiences a parent raising an ASD child might have. The Social Worker can then better assess, empathize and engage parents raising an ASD child.

The Helping Process and Macro practice are used in this research to explain the significance of this research on the Social Work profession.

### Micro Practice Implications

The Helping Process, described by Hepworth, Rooney, Rooney, Storm-Gottfried, and Larsen (2006), begins with exploration, engagement, and planning. At the center of the Helping Process is the idea that as a Social Worker we are developing an assessment that has many layers that include; identifying the problem, acknowledging systems that are affecting the person/family negatively, and identifying and utilizing resources in a way that empowers our clients to feel motivated to thrive. This study has identified a need to hear and understand a parent's experience in accessing resources for their ASD children. In order to apply the Helping Process to maximize the benefit to the client this research intends to provide information that will help develop better assessment and engagement techniques.

As a result of documenting the experiences of parents this study will contribute to Social Work practice, policy and research as described by the Helping Process.

## Macro Practice Implications

"One person can start a movement, but it takes others to fully implement the changes" (Haynes, & Mickelson, 2006, p. 116). The future success of children with ASD relies on the services they receive in early intervention and throughout the early years of development. The literature review conducted by this researcher clearly points to a gap in understanding how parents are connecting with services and how they are managing and if they feel the services their child is receiving is adequate. This researcher is intended to add to the body of knowledge available to professionals. Not only increasing the understanding of a parents experience accessing services but also by putting a focus on a population that depends so heavily on services for success that hopefully more services are created and made accessible to families in need. Macro Social Work is an invaluable service to the ASD population, and needs to continue to grow and learn as the ASD population has.

# CHAPTER TWO

# ENGAGEMENT

## Engagement Strategy in this Research

According to Hepworth et al. (2006), effective communication is crucial in developing a working relationship with a client. Without good communication a participant in the research may guard information and the interview will not be beneficial to the research or the participant. It is vitally important to build rapport by being open and honest about the research and its intentions.

Conducting interviews using a cohesive, relevant, questionnaire to involve participants will play a role in the continued engagement of the participant. The interview should feel relevant to the parents concerns and/or experiences. The researcher needed to show empathy at the appropriate times and demonstrate active listening. It was important to create an atmosphere where the participant feels like he or she is being allowed to speak freely and impact a change to benefit the larger community of parents raising ASD children.

This research project acknowledges the key to success in qualitative research is through engagement of the participant in the study. It is the intent of this research project to be a voice for parents raising ASD children and be as effective as possible in gaining the necessary information to do so.

## Self Preparation

This researcher has been self-preparing continuously throughout the last six years by conducting regular research on the ever changing forum that is ASD. This researcher has been immersed in the ASD community in an effort to be empowered and to empower other parents in the task of parenting an ASD child. Concurrently, this researcher has built confidence in the researcher's ability to engage other parents raising ASD children.

When conducting exploratory research using in depth interviews the researcher becomes the data collection instrument. In preparing to interview participants this researcher researched the most current issues regarding ASD to understand how to best construct a beneficial interview. When conducting the literature review, this researcher identified an area of need in the community of

ASD. That need was for parents' experiences to be heard in a safe and confidential place where they could express their concerns, frustrations and accomplishments in accessing services for their ASD children.

## Concerns Regarding Diversity

ASD is color and monetarily blind. ASD afflicts, Caucasians, Hispanics, African-Americans, Asians, and all other ethnicities. ASD can afflict anyone with any income, wealthy or poor. ASD afflicts boys, girls, and can occur in more than one child in a family. There are mothers and fathers raising their ASD children in the same household, in separate household and there are single parents raising ASD children. There is no shortage of discussion of diversity when researching the ASD population and their parents. The important thing this researcher did was to acknowledge this diversity, and be sensitive to the diverse cultures, ethnicities and situations. It is also imperative that in order to gather the most relatable and reliable data to include and not exclude as much diversity as time and accessibility allows. Conducting the research at a program in Loma Linda gave the researcher the opportunity to interview a diverse population from Chinese, Caucasian, African American and Mexican, as shown in table 1.

## Ethical Concerns

As a Social Worker valuing other people is at the core of our values and ethics and a review of the NASW Code of Ethics was beneficial throughout the interviewing process. In remaining ethical, it was of benefit to this researcher to understand that ASD can be a highly charged topic and to take into consideration that when interviewing a diverse group, beliefs about ASD can vary from family to family and for the research to remain objective in its goals it is important to respect each family's individual beliefs.

ASD parents can be under an enormous amount of stress. It would be ethically unsound for this research to create further stress. To make certain that the interview was as stress free as possible this researcher utilized supervision to ensure that the interview process was as organized, thoughtful, considerate, and empathetic.

Another ethical concern is that the interview questions are not closed ended, leading or misleading about the direction of the answers. The study needs to remain objective when interviewing and analyzing the data. During the interviews the researcher's goal was to document the story of the parents and not influence the answers the parents might give by changing tone, or inflection of any part of the question.

## Political Issues

ASD is highly political within its own community. Because ASD has no defined cause many families are split between those who believe ASD is caused by vaccination and those who believe it is caused by genetics. The purpose of this study is not to discover the cause of ASD or to encourage or challenge a parent's personal beliefs. However, the research is looking at parents' experience accessing resources and based on what a parent may believe is the cause of their child's ASD, may lead a parent down an unconventional treatment path. Based on the participants and the information they divulged during the interview, the data had different categories or types of services that had been accessed or attempted to be accessed by a small number of parents for their ASD children. Consequently, there was a difference in the accessibility of services depending on the belief of the cause of ASD. It is not the intention of this study to engage in a politically driven discussion, but the study did take into account that it is a possibility for a parent to use the interview as a platform to discuss their beliefs and concerns about the accessibility of a particular treatment course that is based on a controversially belief.

## Summary

In closing, it is important for the researcher to maintain focus on the goal of the study which is to document the experiences of parent's accessing services for disadvantaged children with ASD. Families may have different values or beliefs and may have sought treatments that are not understood by mainstream society, it is the in these difference that the NASW Code of Ethics instills in all Social Workers, and this researcher, the value of difference and respect.

# CHAPTER THREE

# IMPLEMENTATION

## Introduction

This chapter discusses the process this researcher took in preparing for and collecting data applying the Post Positivist Paradigm. This chapter includes information on the study site, sample participants, data collection and data analysis. Also included in this chapter is how this researcher insured that participants' confidentiality was established and maintained.

## Study Design

Utilizing the Post Positivist Paradigm, this study used qualitative research methods, specifically face-to-face interviews. This study explored the experience that parent's raising ASD children have when accessing services. Weinberg (as cited in Morris, 2006) writes that qualitative research, or a face-to-face interview, needs to be carried out in a trustworthy manner. In depth interviews were implemented in this study to allow parents to express their thoughts and feelings. The researcher constructed the interviews to elicit the relevant details of their experience directly related to their journey through accessing services for their ASD children.

## Research Site and Study Participants

This research project was carried out at an agency in San Bernardino County that houses a program providing behavior modification therapy to a range of developmentally disabled children. This program is "based on the Adaptive Independence Model and supports families in addressing behavioral problems that interfere with their child's ability to become fully independent" (Inland Empire Autism Society of America, 2008, p. 23). The program in San Bernardino County is only available to clients of the Inland Regional Center. The program has been offering its services to the special needs community for over 5 years. Currently there are approximately 40 families being served at the Program and children receiving services range in age from 2-17. Families participating in the program are diverse and multicultural. The program offers services in Spanish and English, and early and late classes for younger and older groups.

The second source for gathering study participants was the Inland Empire Autism Society chapter. With the approval of the Inland Empire Autism Societies chapter, a brief description of the research project being conducted by this researcher was placed in the chapter's monthly newsletter. Members were given an email where the researcher could be contacted and could volunteer their participation in the research.

## Sampling

The sample for this study is described in Table 1 below. Participants for this study were selected using purposive sampling. Purposive sampling is when "the researcher looks for study participants who will give the most complete data about the study focus" (Morris, 2006 p. 91). There are 15 types of Purposive sampling; the one that was selected to be implemented in this research was Typical Case Sampling. Typical Case Sampling "used to describe an issue or program to those who are not familiar with it. It would give a profile of what tends to be regular or routine, not a generalizable statement about experiences of the program or issue" (Morris, 2006, p. 92).

Parents who participated in the research project were found in two places. The first place was at the program in San Bernardino County. The second way participants were gathered is through the Autism Society's, Inland Empire Chapter, monthly newsletter. This researcher sampled 11 families, 8 from the program in San Bernardino County and 1 family connected to the Autism Society of the Inland Empire.

Participants who were included in the study are directly involved with the parenting and seeking of resources for a child or children who have a DSM-IV Axis I diagnosis of 299.00 Autistic Disorder. The DSM-IVs criteria for a diagnosis of ASD looks at a persons' inability to engage in social interaction, impairment communication, and use of stereotypical behaviors and with delay or abnormal functioning in at least one of the following prior to the age of 3 years, social interaction, language used in social communication, or symbolic or imaginative play. Lastly, the disturbance is not better accounted for by Rett's Disorder or Childhood Disintegrative Disorder (American Psychiatric Association, 2000, p. 75).

Parent's who wanted to participate in the research volunteered their participation after a brief explanation was given of the research that was being conducted.

Table 1. Demographics

| | Frequency | Percent |
|---|---|---|
| Parents Personal Income | | |
| less than $20,000 per year | 2 | 11.8 |
| $20,001-35,000 per year | 3 | 17.6 |
| $35,001-50,000 per year | 3 | 17.6 |
| $50,001-65,000 per year | 5 | 29.4 |
| $65,001-80,000 per year | 3 | 17.6 |
| more than $80,001 per year | 1 | 5.9 |
| Parents Educational Level | | |
| Some College | 10 | 58.8 |
| Bachelor's degree (undergraduate) | 3 | 17.6 |
| Some graduate school | 2 | 11.8 |
| Master's degree (graduate) | 2 | 11.8 |
| Parents Age | | |
| 17-25 yrs old | 1 | 5.9 |
| 26-35 yrs old | 4 | 23.5 |
| 36-45 yrs old | 8 | 47.1 |
| 46 yrs or older | 3 | 17.6 |
| Missing | 1 | 5.9 |
| Parents Ethnicity | | |
| African-American | 3 | 17.6 |
| Caucasian | 8 | 47.1 |
| Hispanic | 4 | 23.5 |
| Asian/Pacific Islander | 1 | 5.9 |
| Other | 1 | 5.9 |
| County where the ASD Child Resides | | |
| San Bernardino | 13 | 76.5 |
| Riverside | 4 | 23.5 |

| | Frequency | Percent |
|---|---|---|
| Parents Insurance | | |
| No health insurance | 1 | 5.9 |
| Medi-cal | 4 | 23.5 |
| Private health insurance | 12 | 70.6 |
| Childs Insurance | | |
| Medi-cal | 6 | 35.3 |
| Private health insurance | 11 | 64.7 |
| Parents Marital Status | | |
| Married | 13 | 76.5 |
| Single | 1 | 5.9 |
| Divorced | 2 | 11.8 |
| Other | 1 | 5.9 |
| Gender | | |
| Male | 5 | 29.4 |
| Female | 12 | 70.6 |
| Parents Ethnicity | | |
| African-American | 3 | 17.6 |
| Caucasian | 8 | 47.1 |
| Hispanic | 4 | 23.5 |
| Asian/Pacific Islander | 1 | 5.9 |
| Other | 1 | 5.9 |

## Data Collection and Instruments

This study was an exploratory study and data was collected using face-to-face interviews. A series of questions was developed for the purpose of these interviews (Appendix A) to explore with parents their experiences accessing services for their ASD children.

In recognizing the need for exploratory research in the area of ASD children and their parents this researcher began to critically think about and form questions that would guide a participant in an interview on a journey of expressing their story. Topics in the interview included: experience accessing a diagnosis for an ASD child, what agencies the parents have utilized to access services, what services and satisfaction rating on services accessed, and if parents are satisfied with services available to them. As interviews progressed, this researcher made adjustments where needed and included information about their child's medical coverage and how insurance plays a role, or a lack of a role, in providing services to ASD children.

At the conclusion of every interview data on participant's age, ethnicity, marital status, and income was gathered in a demographics survey that the participants filled out.

## Protection of Human Subjects

Protection of Human Subjects was carried out throughout the entire research process. In designing an interview that does not manipulate or cause stress on participants, the research is protecting its participants. When identifying participants it was equally as important to protect the possible participants by informing them of the study's purpose and providing open honest answers to any questions a potential participant may have. Before continuing on with the interview it was vital in the protection of participants that they were informed and agreed to all the stipulations that are required to be a participant of the study by signing an Informed Consent form (Appendix C) by marking an unidentifiable "X" where a signature would normally be required. When conducting the interview and gathering demographics it was important not to include an identifying marks, so that anonymity remains with the participant and identifiable information is not collected.

## Procedures

Before beginning the interviews, the Director of the program set up one of the available therapy rooms, with a desk and three chairs for the interviews to be conducted in. The average length of each interview was one hour. Typically each interviewee was notified the week before their interview of their interview time (the interviews coordinating with the night and time that they were already scheduled to be at the program). Three of the 11 interviews were not associated with the program in San Bernardino County and those two interviews occurred at the participant's home by their request.

Before each interview began the participants were informed that their confidentiality was very important to the interview and research process. After the participant read the informed consent they marked the form with an X to ensure confidentiality of the participant and that they understood the interview would be audio recorded. Following the marking of the Informed Consent with an X, the researcher gave each participant brief instructions asking them to be as detailed as possible about their feelings and experiences accessing services. For example, if a participant was not happy about a service, the researcher requested that they express their unhappiness with detail about why they were dissatisfied with the service. Likewise if the participant was happy with a service, the participant was asked to describe in detail what about the service satisfied them. Another issue that arose was that participants were describing the Program as "here" (being that the interviews were generally held at the program in San Bernardino County) therefore the researcher had to request that participants from the program in San Bernardino County describe where they were and what the service was.

Each interview began with the interviewer, the researcher, engaging participants in finding out more about their personal history: their occupation, where they grew up, and any other family history they wished to share. Each interview was unique in the tone of the interview. There was a wide range of diversity in how open the parents were in discussing and elaborating on their experiences. It was the researcher's responsibility to ensure that each question was answered as completely as the participant was able, without being demanding. At the end of each interview the participant was asked if they had any further information of feelings they would like to share. Generally parents did not offer any further information. After each interview was done recording, every participant was asked to fill out the demographic information (Appendix B), to which each participant completed.

After the interviews were completed, the audio recordings were transcribed. When transcribing the interviews it was important to maintain confidentiality and not to include any identifying information, such as names, so this researcher used abbreviations.

## Data Analysis

After each interview was transcribed, the researcher entered the transcription into Atlas.ti, a software program used to do qualitative analysis by coding/identifying patterns between all 11 of the interviews conducted. The first stage in coding has been identified as first level coding by Grinnell and Unrau (2008). First level coding, or open coding, requires the researcher to allow the information gathered in the interviews to emerge into categorizes and assign meaning or codes to the information (2008, p. 395).

After codes were assigned, the researcher then compiled the information gathered from each interview and wrote a case report on each individual interview, using the codes assigned during the first level coding as headings distinguishing each section of information.

# CHAPTER FOUR

# RESULTS

## Introduction

As noted in chapter 3, 11 case studies were developed and they are described here. They are organized according to the categories that emerged during the open coding analysis. These were services accessed to receive their child's diagnosis, services accessed through A Regional Center, services accessed through their child's school district, and any other possible services accessed that were not tied to Regional Centers or schools. The chapter ends with a summary of parents' feelings about their experience of accessing services for their ASD child.

## Family 1

### Introduction

Family 1 included a single mother (Parent 1:P1) of two ASD children. Before P1 had children she had seen a special report on 20/20 about ASD and believed it was the worst kind of disability. Both of her children are on the moderate to severe end of the spectrum and require 24 hour, constant, supervision, despite the fact that they are 6 (Child 2: C2) and 7(C1) years old. C1 is currently on medication to manage some of their ASD symptoms that were preventing them from fully benefiting from services. Now that P1 is raising two ASD children, she still believes it is the worst kind of disorder because "you know what could help your children, but you can't always access it" (P1, personal interview, February, 2010). C1 and C2 are in the public school system and are consumers of the Regional Center. C1 has recently been placed on medication to subside some their ASD behaviors.

### Diagnosis

In an effort to discover why C1 was not speaking at 2, even after surgery to correct C1's hearing, P1 ignored the pediatricians assessment that C1 was regressing to get attention since there was a new baby in the house, and contacted a family friend who directed P1 to the Inland Regional Center where C1, at the age of 2.9 (2 years, 9 months), was diagnosed with ASD. P1 recognized the signs much sooner with C2 and was able to access a diagnosis through Regional Center at the age of 18 months.

Regional Center Services

P1 has utilized a Regional Centers Services to connect her and her children with behavior modification services that have positively affected C1 and C2's behaviors. Furthermore P1 has received services/trainings from Region Center that have increased her knowledge of ASD.

C1 and C2 were both on the waitlist for a University based behavior program for three years and when they were finally accepted to the program, P1 was happy with C1 and C2's placement at the behavior modification program in San Bernardino County so they did not participate in the University based program. C1 and C2 have participated in the program since each child was respectively three (C1 4 ½ years and C2 3 ½ years), through funding provided by Regional Center. However, recently the Regional Center P1 receives services from has changed their policy, due to budget constraints, which state that Regional Center consumer can only participate in a behavior program for 2 years. Since this policy has taken affect C1 and C2 have been out of any behavior modification services for two months. This lapse in service continues to negatively affected C1 and C2. Currently C1 and C2 are waiting for a new program to begin that brings a behavior modification specialist into the family's home for therapy. P1 is not happy with this program. P1 values the experience of taking her children out of their home, helping them become adjusted to transitioning and incorporating social skills by exposing them to new people and new situations.

Furthermore, P1 is not happy with the overall service Regional Center has to offer. In particular P1 feels frustrated when she tries to contact her Regional Center worker and reports it can take up to a month to get a receive a return phone call. In the end though, P1 reports that she would call Regional Center to access future services, not knowing who else to contact.

### Accessing School Services

P1 is in a transitional period with her feelings about her children's public school. P1 for many years felt the school was not providing the appropriate services to her children and often felt helpless about working with the children's school to make necessary changes. For example, P1 felt she had to "beg" for services, like a behavior support program or speech and occupational therapy, which were often denied by the school district because according to the school districts policy "it's not an educational issue" (P1, personal interview, February, 2010).

After many frustrating years dealing with rejection and subpar educational support from her children's school, P1 contacted an adjunct agency to the school district. The goal of the adjunct agency is to coordinate the most effective and efficient service to special education children in their school setting Since a representative from the adjunct agency has been visited out to C1 and C2's school and classroom and made suggestions for change to the school's teacher and principal, P1 feels hopeful and reserved that her children's school and teachers are willing to work with P1 to implement the children's IEP goals in an effective way in the 2009-2010 school year. P1 has already seen improvement with C1's services. C1 has had a goal that Picture Exchange Communication system (PECs) was to be used in effort to encourage communication from C1 since C1's kindergarten year (C1 is chronologically in the 3rd grade now). However, the goal was not being implemented by C1's teachers, but since the representative from the adjunct agency has visited the school C1's teacher has begun to use PECs.

## Other Services Accessed

The cost of services has stopped P1 from accessing private therapies and services for her children. P1 was really interested in a University based speech and asked both Regional Center and her children's medical insurance to cover the cost but was denied and the children never participated in the program.

P1 did access swim lessons through the Y, but they were not tailored to special needs children and C1 and C2 were often given "bad looks," and C1 and C2 did not complete the swim lessons (P1, personal interview, February, 2010).

P1 is unclear about what her children's medical insurance will cover and right now is not receiving any services through insurance.

## Conclusion and Summary

P1 has struggled and was often left feeling frustrated in accessing services for her two ASD children. P1 lost trust with her children's pediatrician after they were unable to recognize the signs of ASD inhibiting an early diagnosis. P1 had learned a valuable lesson from her experience accessing C1's diagnosis that later helped C2 access services earlier, and in P1's opinion slightly decreasing C2's development delays.

P1 has struggled accessing and enforcing services through her ASD children's school and with their IEP. P1 has utilized strength in requesting advocacy through an adjunct agency to the school district and has gained some hope for the future success of P1's relationship with her children's school.

P1 is not accessing any services her children's insurance should be covering, like intense occupational therapy. P1 has accepted defeat in the repeated denials of services instead of educating and therefore empowering her mission to improve the quality of her children's lives. P1 states that she knows that her children's brains are becoming more "solid" every day with less potential to grow and she is worried about her children's ability to learn and be independent when they are older (P1, personal interview, February, 2010).

## Family 2

### Introduction

Family 2 consists of: Mom (P2), Dad (P3), ASD child (6 years old) (C3), and a younger typically developing child. P3 works from home and P2 works as part of the support staff at a local school in their community. C3 attends a public school and is a consumer of Regional Center. C3 is described as being "low functioning."

### Diagnosis

Prior to C3's diagnosis neither P2 nor P3 had any experience with ASD. P3 made a reference to the film, *Rain Man*, as his only knowledge about ASD. So when their child began to flap hands and/or have mechanical or repetitive play, neither had any idea what it meant nor were they concerned by the behavior. When C3's language stopped developing and severely regressing, P2 took C3 to the pediatrician. P2, on reflection, remarked how the pediatrician didn't pick up on any signs that pointed to ASD. When C3's hearing was checked and found to be fine, C3 was taken to a neurologist who diagnosed C3 within five minutes.

### Regional Center Services

C3 is a consumer of Regional Center and has received a variety of services through Regional Center. C3 started with receiving services with an In Home Behavior Program through Regional Center. C3 was then referred to the program in San Bernardino County, for more Behavior Modification services through Regional Center.

While P3 states that he would attempt to access any future services his child needs on his own first, but that he would try to utilize what services and contacts Regional Center had to offer, second.

## Accessing School Services

C3 is in a Special Day Class (SDC) in a public school. P2 and P3 are very unhappy with the services their child is receiving at school. C3 is lower functioning than the other children in the class and requires more assistance in accomplishing tasks. P2 feels she has had to fight for services through the school district and is anticipating resistance from the school when she requests the school provide a one to one aide for C3. P3 has decided that only through her own knowledge of the school systems regulatory system can she access the services her child needs. P3 has started actually reading the Parents Rights she has been given at every previous IEP in hopes that she will be better prepared about her and her child's rights to services in future IEP's.

### Other Services Accessed

C3 has been in a special needs swim class, and is currently in gymnastics for special needs children. At one time C3 might have missed out on gymnastics class because of the high cost. However; P2 and P3 researched funding C3's gymnastics class through Regional Center, but when they were denied P2 and P3 discovered a scholarship program in the Los Angeles area and C3 was awarded a year's worth of gymnastics class cost.

C3 has received several services through insurance. C3 is followed by a neurologist, an ASD specialist, and a dentist that has experience working with special needs children; all covered by C3's private insurance.

P2 has applied with In Home Supportive Services (IHSS) to receive monies for providing 24 hour protective care for her ASD child. This service is available to parents who need to provide protective care because their children run away, or a danger to themselves.

### Conclusion and Summary

Family 2 has strength in their knowledge that they are their child's only advocate and they continue to seek a variety of services. While P2 and P3 are not satisfied with the amount of services C3 is receiving in the school district, P2 has a clear direction and plan of action for achieving the goals she has for her child.

Because Family 2 is very driven they do not rely on the services of Regional Center, but they do access services through Regional Center when it is available.

C3 has private health insurance and P2 and P3 are very satisfied with their ability to access services through their insurance.

## Family 3

### Introduction

Family 3 consists of Mom (P4), Dad, a typically developing child and the youngest child, 7 years old, has mild ASD (C4). P4 is a teacher at an elementary school. C4 is a consumer of Regional Center, attends a public school and has private health insurance.

### Diagnosis

P4 had some special education training as part of her educational track prior to C4's diagnosis. From her training P4 came away thinking ASD meant a child was mentally retarded and out of control, and never recognized her child's mild symptoms of slow language development and lack of response to verbal cues at the age of 2. C4's pediatrician recommended that P4 take her child to be assessed for ASD. P4 was directed to Regional Center where C4 was diagnosed as mildly ASD. P4 was in disbelief, stating that "my child is normal."

Regional Center Services

C4 is a consumer of Regional Center and received early intervention services from the time C4 was 2 ½ until the age of 3. Since then C4 has had little contact or services through Regional Center. When C4 was five, P4 spoke to her Regional Center worker and requested some behavior modification because C4 was beginning to have frequent meltdowns. C4 was placed on a waitlist for the behavior modification program in San Bernardino County where there were for 2 years.

P4 also was told by her first Regional Center worker about Respite care (Regional Center pays an agency or family member to relieve the parents of parenting for a given number of hours in a month), but P4 was unclear what it was about and when her Regional Center worker was changed her new worker did not explain the service any clearer and P4 never requested the service. Two other services that were offered by Regional Center was a mentor program where a community member would take C4 out into the community for social development, and a camping trip with other ASD children, but since the budget cuts in the Regional Center C4 has access to, both services are no longer being offered because they are community or social programs and are not focused on behaviors.

### Accessing School Services

C4 is in a multi-grade SDC class. P4's main concern has been C4's language development, and has fought with C4's school to provide an adequate amount of speech therapy to C4. After the school was not going to give C4 speech twice a week as requested by P4, P4 was not going to sign C4's IEP at which time the school compromised and decided that speech once a week with consultation by the speech therapist in C4's class twice a month was agreeable. C4 does not receive occupational therapy or any other services through school.

### Other Services Accessed

P4 has paid out of pocket for 6 months of private speech therapy. P4 has not accessed any service for C4 through insurance or other means.

### Conclusion and Summary

P4 has sought limited services for C4 and has not been satisfied with the services offered by both the school district and Regional Center in the past. P4 is, however, happier with the school's service now that they have compromised on the amount of speech therapy C4 receives.

It is possible that P4's early misunderstanding about ASD has affected what services she seeks for C4. P4 believes that C4 is more stubborn than Autistic and therefore she seeks therapies and services related to the concerns she feels are immediate and relevant, i.e. speech and behavior modification, but lacking interest in services like occupational therapy for fine and large motor skills, or Applied Behavior Analysis (ABA).

## Family 4

### Introduction

Family 4 consists of Mom (P5), Dad (P6), ASD child (C5), 9 years old, and a typically developing child. Both parents are employed in education. P5 describes her family as "typical." C5 is a consumer of Regional Center, in public school and has private health insurance.

### Diagnosis

Family 4 was referred to Regional Center by C5's pediatrician. Family 4 has kept a good rapport with C5's pediatrician who they continue to trust for advice and information. P5 says that they are not involved with any other ASD organizations or other services because they prefer to focus on their child rather than the bigger picture of ASD and that has worked out for them.

### Regional Center Services

C5 is a consumer of Regional Center since their diagnosis at the age of 2 years. From the age of 2 and until they were 3, C5 received early intervention services at home through Regional Center.

P5 and P6 have mixed feelings about the services offered through Regional Center. Currently C5 is in behavior modification program in San Bernardino County. C5 was put on a waitlist for both the behavior modification program in San Bernardino County and a University based behavior program, and the program in San Bernardino contacted them first. Family 4 is happy with the program in San Bernardino County, but they feel that the Regional Center is disconnected about the requirements the services they refer parents to sometimes. For example, the Regional Center has referred Family 4 to receive respite care, but they were denied based on their income. P5 often feels that their child should receive services because they are ASD not because they have money or not. While Family 4 has sufficient income to meet their needs, P6 reports that does not mean they have to pay for expensive therapies and other services their child may need.

Family 4 has been recently notified by Regional Center that their funding for the behavior modification program C5 attends in San Bernardino County will terminate due to the Regional Center's new policy and budget restraints stating that a consumer can only participate in any one program for more than two years. Furthermore Regional Center is requiring all parents who want to have their child participate in any behavior modification program to take a parent training class. P5 and P6 have been unable to attend the parent training due to scheduling issues.

### School Services Accessed

C5 is a student at a public school in an SDC class. There is a range of disabilities and grades that the SDC class serves, but the class size is significantly smaller than the average fourth grade class C5 would typically be in. Since C5 was in second grade she has participated in "mainstreaming" or inclusion which involves transitioning

C5 into a typical class room for a specific amount of time or for a particular subject C5 might have strength in. C5 receives speech therapy at her school and thus far Family 4 is satisfied with the school services. Recently C5 has begun to regress and speech has become less clear and more mumbled. P5 and P6 are waiting to see if C5 is going through a phase/stage or will require more intense speech therapy.

### Other Services Accessed

Through C5's private insurance, C5 has received Occupational Therapy. P5 and P6 report having no difficulties accessing services through their insurance. P6 speculates that is probably because the insurance gets their premiums from the family so in essence they get paid.

C5 also has been referred to a dentist that specializes in working with special needs children. Family 4 feels more comfortable accessing services that are designed or prepared to deal with special needs children. Their experience with services not prepared for special needs children has been limited but stigmatizing as many people do not understand why their child is acting out or isn't "under control" (P5, personal interview, February, 2010)

### Conclusion and Summary

Family 4 had a relatively easy time accessing a diagnosis. This is in part that their pediatrician recognized the signs of ASD and both P5 and P6 trusted their child's pediatrician. Family 5 has been fortunate to have private insurance and an informed pediatrician. Family 4 relies heavily on the recommendation of the pediatrician and Regional Center limiting C5 to what services others suggest instead of educating themselves on ASD and what services are most vital to their child. That being said, Family 4, up to this point, has been generally satisfied with the services C5 has received. P5 admits that she is concerned about her child's future dependence, but rationalizes that it is normal she just doesn't think about it as often with her typically developing child.

## Family 5

### Introduction

Family 5 consists of Mom (P7), Dad (P8), and their ASD child (C6) who is 5 years old. Dad works in a city job and Mom stays at home with C6. C6 attends public school, has private insurance and is a consumer of Regional Center.

### Diagnosis

P7 had a lot of experience with tutoring ASD children prior to having her own child. But that didn't take away the feeling of loss when C6 was diagnosed with mild ASD. P7 and P8 were grateful for P7's experience with ASD and with the school district after her child's pediatrician recommended that their child be tested for ASD, gave them a referral to Regional Center, and were denied an assessment by Regional Center over the phone. P7 knew exactly what to do because of her years with the school district. P7 called the their local school district office and scheduled an assessment for C6 knowing that the school is required to assess children at the age of three if there is possible delay in development. C6 was assessed and diagnosed within a month, and P7 and P8 were very satisfied with the quickness and thoroughness of the assessment.

### Regional Center Services

Despite the denial of an assessment earlier in C6's life, P7 and P8 use the resources Regional Center offers to the advantage of their child. C6 started at Regional Center with receiving an in home behavioral program and is now attending a behavior modification program in San Bernardino County with funding from Regional Center and is very happy with the behavior modification that C6 is receiving there. C6 is on the waitlist, and has been for three years, for a University based behavior modification program with referral from Regional Center. Family 5 has 24 respite hours a month as approved through Regional Center. In addition to C6 receiving service, P7 and P8 have also attended seminars that were paid by Regional Center for furthering their knowledge of ASD.

Recently Family 5 has asked for more support regarding their desire to involve their child in more social activities. C6's workers advice was for the family to "tap into the community." Family 5 was disappointed to hear that. Family 5 feels that the community does not offer much in support of or appropriate for special needs children. Despite the lack of social opportunities Regional Center offers both P7 and P8 agree that C6's current worker has been helpful and they would contact her first in the event they were looking to get into any other programs.

### School Services Accessed

P7 is very happy with the services provided through the school district and states no services have been denied that they have requested. At one time P7 did request occupational therapy but P7 was satisfied with the school districts explanation that because P7 is requesting it in relation to behavior it would not be a service would provide since it was not an educationally based need.

C6 has transitioned from a mainstream preschool class to an SDC kindergarten class this year. C6 also receives speech at his school. P7 is completely happy with C6's progress and services at his school.

### Other Services Accessed

Family 5 is heavily involved with the ASD community and the accessing of special events and services offered through a wide range of organizations. Family 5 is involved with the Autism Society of America (ASA). Family 5 attends the ASA's sensory friendly movie nights, where the films volume is turned down lower than normal and the lights stay on. They walk with family in the Autism Speaks walkathon every year. P7 attended a mommy group when C6 was younger and P8 currently attends a father's support group for fathers of children with ASD. Family 5 also has accessed handicapped passes to Disneyland, making the day much more enjoyable for the entire family. They also attended a free trip to Legoland through Talk About Curing Autism (TACA), Jenny McCarthy's organization for ASD.

C6 has private medical insurance and has been denied services for occupational therapy and the P7 wishes that the medical system would change their opinion of ASD and accept some cost for therapies. C6 was also denied a pressure vest through medical insurance.

P7 and P8 applied for, but were denied Social Security Disability for C6 because their income was too much.

## Conclusion and Summary

When a denial of service to get an assessment from Regional Center could have discouraged Family 5, they used the resources they knew were out there and were able to have C6 diagnosed through the public school system. Family 5 has continued to grow their knowledge of services available and accessing many resources and services available to them through networking and participating in the ASD community. Still with Family 5's tenacity for accessing resources they have found that it does not get them everything they want for their child. Family 5 would like to have C6 in occupational therapy, and get a pressure vest but after denials from three agencies (Regional Center, insurance and school) they have not found a way to access the therapy or product.

## Family 6

### Introduction

Family 6 consists of a single mom (P9) and her ASD child (C7) who is 10 years old. P9 is a student and had no knowledge or experience with ASD prior to her child's diagnosis, only a reference to the film, *Rain Man*. C7 is a consumer of Regional Center, has medi-cal, has recently been transferred to a non-public school, and is on medication to manage some of his ASD behaviors that prevented C7 from participating in beneficial services fully.

### Diagnosis

Before C7 was diagnosed, P9 had no experience or knowledge of ASD. P9 regrets that she didn't get C7 diagnosed sooner and would like to encourage other parents to know the signs of ASD and seek help if they suspect anything. C7 was referred to Regional Center to get a diagnosis by their pediatrician at the age of three. C7 was being seen by a pediatrician for frequent ear infections and C7's hearing was in question. P9 remembers this was a busy time of going to many different referrals trying to understand what was wrong with C7. After C7 was diagnosed with ASD, P9 appreciated the symbol of a puzzle piece representing ASD because she feels frustrated and unclear about the disorder.

### Regional Center Services

P9 is grateful to have a responsive and informed Regional Center worker. Currently C7 is attending a behavior modification program in San Bernardino County. P9 is moderately happy with the program but wants to change some of C7's goals to more challenging goals. C7 was also on the waitlist for a University based behavior modification program for two years and has never accessed the service. P9 would like to access more social activities through Regional Center, but as P9 understands it because of the Regional Center's budget cuts there are no services available to C7.

### School Services Accessed

C7 was recently moved to a non-public school because their behavior was frequently inhibiting their ability to learn. P9 is unhappy with change of service. The school focuses on managing behaviors and is not educationally driven. C7 is in a class that is specifically for ASD, however; P9 feels that C7 is regressing developmentally and feels that C7 is not getting any social interaction like he did at his public school. The goal of the non-public school is to get the kids' behaviors under control so they can return to their regular public schools.

### Other Services Accessed

C7's Medi-cal is currently covering the cost of speech therapy. P9 has to go through the process of renewing the referral to speech therapy after only 10 sessions, which consists of the C7 going to a neurologist and waiting for a new referral to go through, losing time of service in the meantime.

The cost of services has stopped P9 from accessing several services. P9 expresses her belief that ASD is a business and while services promise a cure they are pricey and unaffordable to her and her child. P9 would like to access an expressive communication program and a more intense behavior therapy for C7, but both are out of her financial reach.

## Conclusion and Summary

"You're trying to get as much services as possible. You're wondering if you're doing the right thing" (P9, personal interview, February, 2010). With so many services available and so many inaccessible, P9's statement sums up her feelings about her concern of what the effect will be on her child given the services accessed and those services that have not been accessed.

P9 has made tough decisions recently to put her child into a non-public school and is having a hard time adjusting to the idea that her child might not ever be independent or on a "normal" educational track. P9 has really strived to provide access to all the services she can, and that will benefit her child. P9 has accessed services through a wide variety of avenues, Regional Center, insurance and school.

# Family 7

## Introduction

Family 7 consists of: Mom (P10), Dad, a typically developing child, and a 7 year old ASD child (C8). P10 is a stay at home Mom, while Dad works outside of the home. Neither parent had any previous experience or knowledge of ASD. Parents only a reference to ASD was the film *Rain Man*. C8's older sibling has been described as very helpful and understanding when managing C8's behaviors. C8 is a consumer of Regional Center, goes to public school and has Medi-cal for insurance.

## Diagnosis

When C8 was 2 years old they were seen by their pediatrician for lack of language development and seemed painfully shy around everyone but their mom. C8's pediatrician walked in the patient's room, observed C8's behavior for a brief time, and told P10 that C8 showed signs of ASD and walked out of the room. P10 was referred to an ASD clinic that was covered by C8's private insurance, at the time, by the pediatrician and was given no further information by the pediatrician about what ASD was. After nearly four months of waiting for the referral to the ASD clinic, P10 spoke to a friend who worked for

Regional Center and encouraged P10 not to waste any more time and to contact Regional Center for an assessment. Regional Center came to see C8 in their home and was diagnosed with mild to moderate ASD at the age of 2 years and 10 months.

### Regional Center

C8 started receiving services with Regional Center immediately after diagnosis. P10 credits knowing someone who works for Regional Center, with her success in accessing many beneficial resources (a behavior modification program in San Bernardino County, a University based behavior modification program, Respite care, and a variety of workshops and seminars) for C8. P10 states that, "They don't want to offer you anything unless you ask" (P10, personal interview, February, 2010).

P10 has only experienced being denied one service through Regional Center and that was an ABA program that she desperately desired for her child, so much so that after much persistence, her request was eventually approved. P10 expressed that she does not request services unless C8 would benefit from them and the service is something she cannot provide on her own, so that other families who may need the service have the funding available to access the service.

### School Services Accessed

C8 has been attending public school since the age of 3. C8 started in a preschool structured exclusively for ASD children. At which time C8 began to receive speech and OT services through the school district, which C8 continues to receive to date. When C8 was ready to transition into Kindergarten P10 struggled with the choice of putting P10 into an SDC or continue with a class designed for ASD children only. In the end P10 placed C8 in the ASD class and has been completely satisfied with her choice and with C8's teachers.

### Other Services Accessed

When C8 lost his private insurance due to family circumstances, P10 was unaware that Medi-cal would cover C8 and could not deny him, although they could and did deny the family, until a peer informed P10 of the available resource. P10's was adamant that if you don't know someone on the inside or who accessed the service there is so much available but you don't know about and can't access until someone says, did you know…? Another insight P10 shared about the ability to access services was that she feels there are services out there that are accessible, but not affordable and therefore she has to rely organizations like Regional Center and insurance to cover the cost to the services she seeks for C8 (P10, personal interview, February, 2010).

P10 is involved with the Autism Society and over the years most of her friends are peers, in that most of her friends have an ASD child and she gains a lot of information about services through her networking with them.

## Conclusion and Summary

P10 has dedicated the last few years of her life to her child's development, quitting her 10 hour a day job, to be home providing constant therapy to her child. P10 was very emotional, crying about her child's progress in treatment and the struggle she has faced in accessing as many beneficial services as possible. P10 used words like, "frustrated" and "stressful" in describing her experience in accessing services. However, with P10's determination and belief that she is the only one who is going to do everything in their power to help C8, she has accessed many services that have greatly benefited C8. P10 is proud of her child's accomplishments thus far and continues to seek services that will continue to benefit C8 within her family's budget or that can be accessed through C8's insurance or Regional Center.

## Family 8

### Introduction

Family 8 consists of a Mom (P11) who is a divorced parent, raising her 16 year old, severely ASD child (C9). P11's only reference to ASD prior to her child's diagnosis was the film, *Rain Man*. P9 is on the severe end of the ASD spectrum and has very little verbal skills and is medicated to manage some of their ASD behaviors. C9 is a consumer of the Regional Center.

### Diagnosis

When C9's pediatrician told P11 that C9's gender typically develops language slower, after P11 expressed concerns about C9's lack of language development, she trusted the pediatrician and waited 8 months before bringing C9 back to the pediatrician. When C9 was brought back to the pediatrician with no further development than the previous visit, C9 was referred to a neurologist, where they were diagnosed with ASD, at the age of 2.3, after a 10 minute assessment. "I wish C9 would have been diagnosed earlier, when I initially took them, cause I feel like we lost some time there" (P11, personal interview, February, 2010).

### Regional Center Services

C9 is a consumer of Regional Center and has been since the age of 3 years old. P11 reflected back on a University based behavior modification program, participation funded by Regional Center, as being one of the services her and C9 benefited most from. P11 gained a lot of support from other consumers at the University based program which helped her access other services that benefited C9.

Unfortunately not every service accessed through Regional Center has been easily accessed or kept by C9. Currently C9 participates in a behavior modification program in San Bernardino County and has for five years. Since Regional Center's policy change that only allows for participation in any one program for no more than 2 years, Regional Center has informed P11 that C9 will no longer be able to attend the behavior modification program in San Bernardino. P11 was not accepting of this new policy change. P11 spoke with her case worker who replied to P11's request by stating that if C9 is still having behavior problems after 5 years then the program isn't working for them and gave P11 a list of other services available. After P11 called and discovered all the services listed on the flyer were no longer in service, P11 called her case workers supervisor and was able to negotiate 6 more months of service at the behavior modification program in San Bernardino, and P11 plans to fight again if Regional Center won't approve another 6 months.

### School Services Accessed

C9 has recently begun their first year in high school. Previously C9 was in classes specifically for ASD children, but now C9 is on a functional track of education and is in a mixed disability, SDC class. P11 is very happy with the C9's teacher, class and services being given at school. C9 receives speech consultation, which at C9's school is the teacher incorporating speech into the class curriculum.

P11 wasn't always happy with C9's high school placement. For the first four months of school C9 was placed at a high school where P11 felt they were being babysat more than taught. P11 called an emergency IEP and requested a change of placement. The school was not forth coming with other placement options or very willing to change C9's placement. P11 was frustrated with school system and felt "strong armed," but P11 felt that it was important for her child to have placement that could better help C9 reach their IEP goals and she never gave up, and eventually they accommodated her request and P11 is much happier now (P11, personal interview, February, 2010).

### Other Services Accessed

P11 has tried diets, gluten and casein free, and vitamins on her own trying to reduce her child's behaviors. C9 has been to the Drake Institute for neuro feed back tests, through insurance. C9 has participated in services with a non-profit clinic through a University for speech therapy; the cost was a donation to the clinic, but C9 was kicked out of the program when his behavior became aggressive. P11 would like to try to replace the speech service or attempt to get him back into the same program now that he is on medication to help control his aggression. Currently C9 is in a type of music therapy called, Mentraknome Therapy, which P11 is paying for out of pocket. P11 states she is open to anything, if she thinks it might help she will try it.

### Conclusion and Summary

P11 has been involved with accessing services for her ASD child for many years. P11 was saddened when discussing the experience she had accessing a diagnosis for her child, really upset about the lost time between concern and diagnosis. Despite the loss of time P11 has strived very hard in accessing and implementing many different services with her child. P11 reflects that what works for one child might not work for another, so you have to keep looking and trying.

P11 has had to accept that her child will more than likely never be independent, but she P11 is a fighter and never stops looking for a treatment or a therapy that might help her child become more independent.

## Family 9

### Introduction

Family 9 is a family in transition. Mom (P12) is currently separated from Dad, and together they have 3 typically developing children and their fourth and youngest child (C10), 5 years old, has been diagnosed with moderate to severe ASD. Prior to C10's diagnosis, P12 had no experience with ASD. C10 is a consumer of

Regional Center, attends public school, has Medi-cal for insurance, and has recently started medication to manage some of his ASD behaviors.

### Diagnosis

C10 was being seen by their pediatrician for possible hearing loss when they were just 18 months old, but the pediatrician suspected another possible disability and C10 started receiving services for an early intervention program. During that time P12 was taking C10 to get EEG's done, hearing tests, and even chromosomal testing done. When C10 turned 3 and there was little progress made in their language and other cognitive development, C10 was referred to Regional Center where they were diagnosed as having moderate to severe ASD.

### Regional Center Services

C10 is a consumer of Regional Center and has been since they were 3. Regional Center has provided the resources for C10 to attend a behavior modification program in San Bernardino County, and C10 has been on the waitlist for a University based behavior modification program for two years waiting to access that service.

P11 would contact her Regional Center worker first if she was interested in any other programs to discuss how to access the service. Overall P11 is happy with the Regional Center services.

### School Services Accessed

C10 is in a class especially designated for ASD children. C10 receives speech and OT services from school. P11 discussed that she isn't sure if C10 gets all the services they should. P11 believes that it is possible that the school doesn't tell her about all the services the school offers but she has resolved that what the school voluntarily offers is ok. P11 has only recently learned, by participating in a parent support group that C10 might not be receiving all the services needed or available.

### Other Services Accessed

P11 has accessed supportive services through IHSS, and receives money for providing 24 hour protective care of her ASD child. C10 also gets Social Security Disability for the financial support of C10.

### Conclusion and Summary

Receiving a diagnosis for C10 took a lot of time and energy, P12 felt frustrated and passed around by the different agencies.

P12 readily admits that she is not aware if C10 is receiving all the necessary or appropriate services. However P12 reports that she is happy with all the services C10 is and has received from Regional Center to school.

## Family 10

### Introduction

Family 10 consists of Mom (P13), Dad, their oldest child has Asperger's, their 6 year old ASD child (C11), and their youngest child is a toddler and is receiving early intervention. P13 is a stay at home and Dad is in the military. Neither parent knew anything about ASD prior to their children being born. C11 is a consumer of Regional Center, goes to public school, and has military health insurance.

### Diagnosis

While P13's oldest child was receiving early intervention treatment, the service provider recognized that C11 was showing signs of ASD and began receiving early intervention services, along with his sibling. When C11 was 1 ½ they were diagnosed with ASD through Regional Center. Because P13 had previous experience with her oldest child, the diagnosis was made sooner.

### Regional Center Services

P13 is very satisfied with her Regional Center worker and the services that C11 is accessing. P13 trusts C11's Regional Center worker to inform her when C11 needs to be accessing a service or if a service becomes available.

P13 has tried to qualify for respite care, but with two other children that would not be covered, respite care is impractical.

### School Services Accessed

C11 attends a public school and is in a special class for ASD children only. C11 receives speech and OT through his school. P13 is happy with C11's school and all the services accessed through the school.

### Other Services Accessed

P13 has accessed support groups services to gain peer support and to gather information about ASD and possible treatment services. P13 has also discovered a sensory play room, close to her community. Sensory Time is basically a large play room with sensory friendly toys that are meant to help ASD children modify sensory seeking/avoidant behaviors.

## Conclusion and Summary

Family 10 relies on their Regional Center case worker to recommend and disclose to them all the available and appropriate services for their ASD child at home and at school. This might be because Family 10 has 2 diagnosed special needs children and their third is being monitored for possible developmental delays, and P13 could be overwhelmed. P13 did express that "ASD is a hard disorder to manage because you don't know where or why behaviors are happening and you don't know what to expect, like with mental retardation you know that your child has a cap on learning, but with ASD you don't know if your kids not gonna sleep for days at a time. You don't know if he's gonna meltdown for an hour or five hours" (P13, personal interview, March, 2010).

P13 states she is happy with all of the services she and her children have received through varies avenues; early intervention, insurance, school, and Autism Society. The only service P13 is disappointed in not being able to access is respite care through Regional Center.

## Family 11

### Introduction

Family 11 is a Mom (P14), a Dad (P15), and their 4 year old ASD child (C12). P14 works in the food service industry and P15 is a real estate agent. Neither P14 nor P15 had experience with ASD prior to their own child. P15 has poured himself into research about ASD and has determined that his child's ASD was caused by a combination of an "overload of toxins" in the immunizations C12 received as well as a possibly heredity factor. P15 states they are receiving two types of interventions; the educational kind and the other is the physical intervention. C12 is on a gluten free diet, receives services from Regional Center, a public school, and has private health insurance (P15, personal interview, February, 2010).

### Diagnosis

The first person who recognized that C12 might have ASD was P15's sibling. P14 was offended and began to resent that family member, while P15 begun researching and compiling call sheets of all the numbers and agencies he could gather that had information about ASD. After discussing P15's concerns with C12's pediatrician, the pediatrician referred C12 to the director of assessment behavior modification program in San Bernardino County. While the director did not diagnosis C12 he recommended that the family seek early intervention services. After a short time of being in early intervention program, C12 was diagnosed by Regional Center as having ASD. P14 finally realized her child needed help and began to work with P15 in accessing services for C12.

### Regional Center Services

C12 is a consumer of Regional Center and receives services through Regional Center at a behavior modification program in San Bernardino County. At one time C12 was on the waitlist to begin services at a University based behavior modification program, but Regional Center made Family 11 choose which program they wanted C12 to participate in, and since they had already begun the program in San Bernardino County and preferred the setup of services from the program in San Bernardino they chose to stay with their current service.

## School Services Accessed

C12 started going to preschool when they were 3 and were receiving behavior modification through an adjunct agency with the school district. In the last year, C12 attends preschool in the morning and goes to an SDC class in the afternoon. Family 11 is impressed with the services they have received from the school district. C12 has a one to one aide, he gets speech and OT services and his SDC class has the fluorescent lights covered with filters for children with sensory problems and overall P14 states that it is a "dream" class (personal interview, February, 2010).

The only experience Family 11 has had with being denied a service through the school was when the occupational therapist refused to increase C12's service from once a week to twice a week. Family 11 accepted the denial and sought additional OT time through insurance.

## Other Services Accessed

Through private insurance C12 has accessed OT and speech services in addition to what they are receiving at school. P15 reports that it wasn't easy to access services through insurance but believes it is how you ask for something and your persistence that gets you the services. The one service C12's insurance denied them for was to see a Defeat Autism Now! (DAN!) specialist because they do not recognize DAN! as a valid treatment.

Family 11 pays for C12 to see a DAN! specialist out of pocket. The DAN! specialist is a neurologist who treats C12 by changing their diet and adding supplements. Family 11 is very satisfied with the DAN! treatment and report they see significant changes in their child's abilities since being with DAN! and with their own health as well, as they follow the regiment also.

C12 participates in ski lessons through a private service. And Family 11 has provided C12 with a variety of sensory tools in their home, like a trampoline and swing which provide an outlet for sensory seeking behaviors.

### Conclusion and Summary

C12 has been projected to be on a good trajectory by the professionals and their parents. Family 11 has explored alternative treatments and believes their child has greatly benefited from their choice to detoxify and participate with DAN!.

Family 11 has had a relatively easy time of accessing services through all avenues. P15 credits that to being well informed and asking for things in an assertive but cordial way. Family 11 may have a view of ASD that does not follow mainstream but for them it is working and they have found success. When insurance or the school tells them "no we can't provide that service," Family 11 seeks other means to fulfill their need (P15, personal interview, February, 2010).

## Case Presentation Summary

After documenting on the vast array of experiences a parent of an ASD child may have when attempting to access necessary and functional therapies and treatments, this researcher summarized experiences following the topics of diagnosis, Regional Center services, school services, and other services sought by families interviewed in this research. Included in each summary are recommendations for micro and macro practice of Social Workers working with families with ASD children.

## Diagnosis

The ability of a child's family and pediatrician to recognize signs of ASD early are essential in a child receiving early intervention services. Many parents involved with this study had no experience with ASD prior to their child's diagnosis. A number of parents referenced the film, *Rain Man,* as the only representation of ASD they had ever seen. Other parents had experience, yet when their own child began to show signs of ASD they were blinded by either mild behaviors or compounded medical issues. Many of the parents involved in this research relied on their pediatricians to recognize developmental delays that they were unaware they should be concerned about. Several parents were fortunate to have observant, compassionate pediatricians who were able to refer the parent to other agencies, often Regional Center, for diagnostic services. On the other hand, a few parents were very disheartened by their pediatricians' inability to recognize the signs of ASD, steeling valuable time of treatment for their child.

Parents' trust their child's pediatrician's knowledge and expertise. And sometimes that trust blinds parents to the unequivocal truth that pediatricians are not without flaw. The education of both parents and pediatricians, by macro Social Workers, on the early signs of ASD can stop hundreds of thousands of children from receiving late diagnosis and decreasing the amount of time lost not accessing services.

## Regional Center Services

Every participant involved in this research, accesses Inland Regional Center for imperative services for their ASD children. Regional Centers is a cradle to grave agency and provides millions of families with information, diagnosis, seminars, education, case management, referrals, and financial support. Regional Centers are the first contact for many families who participated in this research when a need arises for a service or access to information. Many participants who report a good experience with Regional Center credit having a knowledgeable and supportive case worker. A good case worker, as documented in this study, is a case worker who calls the family with information about new or applicable services for the child and a case worker who responds quickly to the families phone calls.

Unfortunately the Regional Center that directly serves many of the participants in this research has experienced significant financial cut backs. A key service many parents want for their ASD children, social activities, have been completely written out of the scope of service of the Regional Center these family's access. ASD is marked by social impairment and to treat an ASD child completely, social activities are key to the development of lacking social skills. The Inland Regional Center regulating time spent in a particular service has also negatively affected a few of the participants interviewed. Many families are seeing developmental growth participating in the Family Interact Program a behavior modification program in San Bernardino, but are being asked to discontinue their participation because of new regulations on time in one service.

Families are dependent on Regional Centers for financial support to vital services. Many families do not know how to access services outside of a Regional Center. For that reason it is important that Social Workers in the role of case managers be informed about the available services and empathizes with families on their journey accessing services for their ASD children.

## School Services

A school's willingness to work with families accessing services for their ASD children varies from school to school and district to district.

There is a group of families interviewed that reported they had wonderful, supportive schools. Parents in this group had ease in accessing services for their children like speech therapy and occupational therapy. A strength these parents expressed was their collaborative relationship with the school staff involved with their child's IEP. These collaborative families were rarely denied services they requested from their child's school, and were able to negotiate any differences that arouse. It is important to note that no family accomplished anything positive with a school district without a cooperative and supportive school. One family reported that being educated about the services and their parent's rights was instrumental in having a good relationship with the school.

Some parents on the other hand had a very difficult time accessing services through their children's school. Parents who described not having a supportive school described getting services as having to "fight" for them. Often these parents did not have a working relationship with their child's school, whether by the parent's choice or the schools it was not documented. Agencies like SELPA exist to provide support to parents and schools to ensure that IEP's are being implemented correctly. Only two parents reported accessing SELPA; one parent did so because their child's school was not in compliance with their child's IEP, and the other took advantage of seminars and educational resources SELPA offered.

Social Workers in schools are crucial advocates for special needs children. While many schools do not have a school Social Worker there are other agencies like the Area Boards and TASK who advocate for special education rights for special education children. Parents should be well informed of their rights and know how to access an advocate if they feel they are not able to advocate effectively for their children's rights.

## Other Services

Families were very diverse in their willingness and ability to access services on their own. The families who accessed a variety of services were often the families who sought out information beyond what the pediatrician, agencies like Regional Center, and schools offered them. Family 5 is a great demonstration of a family who is active in the ASD community and who access a variety of services that benefit their child and themselves. Furthermore family 5 has a positive outlook on their child's prognosis and their ability to handle adverse situations.

Families who did not seek services outside of school and Regional Center often were indifferent or complacent about the services they received. Family 1 was not indifferent or complacent, but often did not seek to educate themselves about special education laws or the services her children should have been able to access but were denied through insurance.

A lot of families stated they wish that there were more social activities available, however only Family 2 researched and received a scholarship to fund a gymnastics class.

In conclusion, education is the most beneficial means to which a parent empowers themselves and their ASD child to receive the services the entire family can benefit from.

# CHAPTER FIVE

# TERMINATION AND FOLLOW UP

## Introduction

In conclusion, all participants were informed in the informed consent that they could access the results of this study at the Pfau Library at Cal State University San Bernardino after September 2010. The program in San Bernardino County where most of the research was gathered was given a copy of the study. The results of this study are also going to be displayed at Cal State San Bernardino, School of Social Work's annual poster day in June 2010. This researcher terminated the study with the study's participants at the end of each interview. The researcher will have no ongoing relationship with participants relevant to the research.

## Communicating the Study's Findings to the Study Site

The Director of the program in San Bernardino, where the research for this study was gathered, was given a copy of this study's findings and results.

## Communicating the Study’s Findings to the Study Participants

The Family Interact Program is an "open" group, therefore participants are continually changing. However, each participant was informed at the end of the Informed Consent that the results would be available to view at the Pfau Library, California State University, San Bernardino after September 2010.

## Termination of the Study

The researcher has terminated with each participant individually following the closing of each individual interview. Each participant was informed that following the closing of the research the researcher would destroy all personal information gathered, i.e. the recorded tapes would be destroyed, any paper documentation would be shredded and no names would be used in the writing of the research results.

In terminating the study this researcher has destroyed all audio recorded tapes and shredded all paper that was used during the research, and all files holding research information was permanently deleted from all hard drives, and USBs.

## Ongoing Relationship with Study Participants

The researcher will not carry on a relationship with any of the participants involving the research.

## Summary

This researcher informed each participant that they could access the results of this research at that Pfau Library at CSUSB after September 2010. In concluding each interview, this researcher terminated any relationship involving this research with all of the participants. A copy of this study's findings will be given to the program that facilitated most of the interviews. And finally in June 2010, the study will be presented at CSUSB School of Social Work's poster day.

# APPENDIX A

# INTERVIEW QUESTIONS

## Interview Questions

1. How old was your child when he/she was diagnosed with Autism?
2. How old is your child now?
3. A. Who was your first point of contact when trying to gain access to services for your autistic child when they were initially diagnosed?
   B. Is it the same person/agency now?
5. If you wanted to get into a program tomorrow, who would you contact to gain access to that program? (dr.,irc, agency)
4. What kinds of programs has your child participated in?
5. What programs are your child participating in currently? Are they beneficial?
6. Have you ever been put on a waitlist to receive services for your child and what was the service?
7. Have you ever been denied access to a service you wanted/needed for your child and what was the service?
8. What resources have you utilized to pay for the services your child has participated in?
9. Has money or location ever stopped you from participating in a service you thought your child would benefit from?
10. Do you feel your child is receiving all the services he or she needs? Why or why not?

# APPENDIX B

# DEMOGRAPHICS

**Survey of Demographics**

1. Your age:
   1. 17-25 years old 2. 26-35 years old 3. 36-45 years old
   4. 46 years or older

2. The county in which you and your child resides______________

3. Your personal income is:
   1. Less than $20,000 per year 2. $20,001-35,000 per year
   3. $35,001-50,000 per year 4. $50,001-65,000 per year
   5. $65,001-80,000 per year 6. more than $80,001 per year

4. Your ethnicity:
   1. African-American 2. Caucasian 3. Hispanic
   4. Asian/Pacific Islander 5. Other__________

5. Your educational Level
   1. Less than high school 2. High school diploma or GED
   3. Some college 4. Bachelor's degree (undergraduate)
   5. Some graduate school 6. Master's degree (graduate)
   7. Other professional degree

6. Your health insurance status
   1. No health insurance 2. Medi-cal 3. Private health ins.

7. Your Autistic child's health insurance status
   1. No health insurance 2.Medi-cal 3. Private health ins.

8. Your marital status
   1. Married 2. Single 3. Divorced 4. Widowed 5. Other

# APPENDIX C

# INFORMED CONSENT

# Informed Consent

The study in which you are being asked to participate in is designed to explore the experiences parents of Autistic Spectrum Disorder (ASD) children have when accessing services for their ASD child. This study is being conducted by Barbara Michelle Wood under the supervision of Dr. Teresa Morris, California State University, San Bernardino. This has been approved by the Social Work Human Subjects Sub-Committee of California State University, San Bernardino.

**Purpose:** The purpose of this study is to explore the experience parents have when accessing services for their ASD child(ren).

**Description:** If you chose to participate in this study we can set up a time and place that is convenient for you to complete the interview, at which time I will interview you regarding your experience accessing services for your ASD child(ren).

**Participation:** Participation in this study is voluntary; refusal to participate will involve no penalty or loss of services. Participation may be withdrawn at anytime without penalty or loss of services.

**Confidentiality:** Participation in this study is completely confidential. When you sign at the bottom of the informed consent form you will sign with an "X" as to use no identifiable mark. Your name will not be used in the study; instead a number or letter will be assigned.

**Duration:** The expected time it will take to complete the interview is approximately 40minutes.

**Risks**: There are no foreseeable risks for your participation in this study.

**Benefits**: Participants will help increase the understanding/knowledge practitioners have of parents raising an ASD child and their experience accessing services/resources. In addition, after completing the interview and survey a $5 gift card to Starbucks will be given to participants.

**Recording**: If you chose to participate in this study, it will be audio recorded. When the study is complete the auto recording of your interview will be properly disposed of. If you agree to be recorded please check yes or no below.

**I understand that this research will be Audio Recorded Yes☐ No☐**

**Contact**: If you have questions about this project, please contact my research supervisor, Dr. Teresa Morris, Professor, School of Social Work, California State University, San Bernardino, 5500 University Parkway, San Bernardino, CA 92407, tmorris@csusb.edu 909-537-5561

**Results**: The results of this survey will be available at the Pfau Library, California State University, San Bernardino after September 2010.

_________________________ Date:__________________
Place an "X" here

# APPENDIX D

# APPROVAL LETTER

*José L. Fuentes, Ph.D.*

*Clinical Neuropsychologist*

*Learning Disabilities • Developmental Disabilities • Acquired Disabilities • Neurobehavioral Disorders*

December 2, 2009

To Whom It May Concern:

As the director of the Family Interact Program, I enthusiastically support the proposed research of Barbara Wood for families who have children with Autism.

Families in our center are committed to better understanding the nature of autism and the efficacy of intervention.

We will be happy to collaborate with the development and/or implementation of necessary protocols to support this study.

Please feel free to contact me should you have any questions, or if I can be of further assistance.

Best Regards,

José L. Fuentes, Ph.D.
Clinical Neuropsychologist
Lic. No.: PSY 19230

*24230 Barton Road • Loma Linda, Ca 92354 • 909-796-9300*

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