AUTISM: A NEEDS ASSESSMENT OF SERVICES OFFERED IN HUMBOLDT COUNTY, CA

By

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This project examined the needs of parents/caregivers of individuals with autism in Humboldt County. Quantitative data analysis consisted of a survey examining levels of awareness, importance of, and access to supports and services. Qualitative data analysis explored the extent to which parents of individuals with autism spectrum disorder were accessing available services, the needs of the families and individuals with autism spectrum disorder, and barriers to accessing available services. A needs assessment was utilized to explore the parent-identified needs of individuals with autism spectrum disorder. Findings revealed that parents were unaware of three key services: Paid Neighbors (82%), Paid Roommates (72%), and Infant Stimulation (68%). Parents reported three main services that were most important: Diagnosis (80%), Treatment (80%), and Speech Therapy (76%). Parents identified three significant services that were difficult or somewhat difficult to access were: Treatment (60%), Occupational Therapy (44%), and Education (44%). Parent identified themes surrounding unawareness of services, most important services, and services that were difficult to access had a range of 44% to 80%. Thirteen interviews were conducted with parents, an adult with autism spectrum disorder and service providers. Primary themes derived from semi-structured interviews were access, satisfaction with, dissatisfaction with, and barriers to services. The intent of this project was to design a template for future needs assessments focusing on the lives of the parents and people with ASD residing in rural areas.
Keywords: Needs Assessment, Social Dialogue, Intervention Services, Parental Supports, Access to Services, Importance of Services, Barriers to Services, Autism Spectrum Disorder.
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“People assume that time is a strict progression of cause to effect, but *actually* from a non-linear, non-subjective viewpoint - it's more like a big ball of wibbly wobbly... time-y wimey... stuff.” ~The Doctor
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INTRODUCTION

This Masters project began in the fall of 2013 to research and prepare a needs assessment report based on the perceptions of Humboldt County parents and service providers of individuals with autism. Residents of Humboldt County, a rural Californian community, experience challenges to accessing services due to its geographic remoteness. Acquisition and retention of supports and services are critical to the promotion of health and well-being of all citizens.

Autism is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). Research indicates that autism spectrum disorder (ASD) is known to influence intellectual disability, difficulties in motor coordination and attention, and physical health issues such as sleep and gastrointestinal disturbances. As the fastest-growing serious developmental disability in the U.S., autism affects approximately 1 in 68 American children (www.cdc.gov/ncbddd/autism.html).

These disorders are characterized, in varying degrees, by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors. Approximately 46% percent of children with autism possess average to above average intellectual abilities (www.cdc.gov/ncbddd/autism.html). Twenty-five percent of individuals with autism are considered to be nonverbal, but possess other means of communicating effectively. For individuals with autism, it is imperative that a variety of
treatment options are available to assist them in the improvement of their communication skills and overall physical health.

The Lanterman Developmental Disabilities Services Act (LDDSA) Division 4.5, section 4512 (b) was created and authorized by the governor and California legislature in 1969. Once a person has been determined to be eligible for regional center services, as defined by the LDDSA, an Individual Program Plan (IPP) must be developed within 60 days of the completion of the assessment (WIC§4646). The regional center must help the eligible person develop an IPP. The IPP is an agreement between the eligible person and the regional center. The IPP is very important because it lists goals and services and supports that the regional center will help them receive.

Nationwide budget cuts to social services have impacted the availability of services to individuals with ASD, in particular those who reside in rural areas. The California Supreme Court has ruled that regional centers have wide discretion in determining how to implement an IPP. However, regional centers do not have discretionary power in regards to whether an IPP should be implemented. Limited funding cannot be the basis for denying a service or support (IPP and IFSP Advocacy Manual 2010). As defined by the state of Nebraska, an Individual Family Service Plan (IFSP) is both a process and a document intended to assist families and professionals in a community in their combined efforts to meet the developmental needs of a young child from birth to age three with special need (http://ifspweb.org/index2.html). As long as the regional center has any funds to purchase services, it must provide services and supports based on the consumer’s individual needs and preferences, as determined through the IPP.
process (IPP and IFSP Advocacy Manual. 2010). If the regional center says it denied or reduced services or supports because it doesn’t have enough money, the consumer can request a fair hearing (Cal. V. DDS, 38 Cal.3d 384 (1984).

With a ten-fold increase of autism cases observed within the past 40 years, a needs assessment of services available to individuals with a diagnosis of ASD was vital for Humboldt County, CA. The needs assessment was intended to discern the importance of services to parents, their levels of awareness of these services, and whether they have experienced any difficulty receiving services. The fundamental deliverable of my master’s field placement was to research and prepare a needs assessment report based on the perceptions of parents and service providers of individuals with developmental disabilities, specifically, those with autism and who reside in Humboldt County. Additionally, the needs assessment report will offer recommendations to local service providers based on the conclusions.

My research questions were: To what extent are individuals with autism spectrum disorder accessing services available to them in Humboldt County? What are the needs of individuals with autism spectrum disorder in Humboldt County? What must be done to overcome barriers to services available to individuals with autism spectrum disorder in Humboldt County? The primary purpose of this study was to determine the levels of importance of state-mandated supports and services for parents of individuals with ASD in Humboldt County. The secondary purpose of this study was to determine access and barriers parents of individuals with ASD experience in Humboldt County.
The written report for my field placement contains four major sections that are reviewed through a critical lens: literature; materials and methods; presentation and analysis of the data; and summary, conclusions, and recommendation.
REVIEW OF LITERATURE

An Examination of Autism as Social Dialogue

The intent of the needs assessment is to discern the importance of services to parents/caregivers of autistic children, their levels of awareness of these services, and whether they have experienced any difficulty receiving services. Residents of Humboldt County face distinct challenges to accessing services, due to their isolated geographic location. Peer-reviewed journal articles focused on early behavioral intervention, availability of intervention services, family supports, and barriers to accessing services, were examined to support themes that emerged in the research.

The rapid growth in autism diagnoses has prompted an examination of the historical dialogue surrounding autism and its present day implications and interpretations. The first section of this literature review will provide a brief history of developmental disabilities and their emergence as social dialogue; autism and the evolution of its categorization requirements; and the evolution of policy reform. The second section of this literature review will examine pertinent literature supported by grounded theory and content analysis to explain the benefits of early behavioral intervention, variations in intervention services, availability of intervention services, and parental involvement and support. Kivisto writes “conflict arises from ‘position scarcity’ and ‘recourse scarcity’, and that therefore conflict relations always involve attempts to
gain control of scarce resources and positions.” (2008: 226) Conflict theory was applied to examine the ways in which individuals with ASD interact with institutions and society.

Brief History of Developmental Disability and Policy Reforms

The U.S. Department of Health and Human Services (The Developmental Disabilities Assistance and Bill of Rights Act of 2000) defines a “developmental disability as consisting of a severe, chronic disability of an individual that reflects the individual’s need for a combination and sequence of special, interdisciplinary, or generic services, individualized supports, or other forms of assistance that are of lifelong or extended duration and are individually planned and coordinated” (Public Law 106-402; 106th Congress). The in-depth language defining developmental disabilities has allowed for more Americans to receive supports and services for developmental disabilities. Individuals with developmental disabilities face extraordinary challenges to acquiring social mobility, capital and integration. The acquisition of supports and services are conducive to helping individuals navigate their way through complex social structures.

Social mobility and integration are the cornerstones of special education and/or early intervention services. From 1997 to 2008, the National Health Interview Surveys reported an increase from 0.19% to 0.74% in ASD diagnoses in children, with an age range of 3-17 (Boyle et al. 2011).

This increase in diagnoses has impacted local governments on an economic and resource basis. Family income has been shown to be associated with both the physical and psychological development of children, specifically cognitive functioning and
behavioral competence (Linver, Brooks-Gunn, and Kohen 2002). Children from families living at or below the poverty line were more likely than children from middle to upper middle class families to receive special education or early intervention services. A decrease in government-based interventions disenfranchises children living at or below the poverty line. This is observed when upper to upper middle class individuals do not engage in the same pathways their counterparts with less economic status do when attempting to access services.

The rise in diagnoses has resulted in major policy reforms. In particular, Section 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act (ADA) have been influential in reforming educational practices to level the playing field for disabled youth. Federal legislation mandates that disabled students receive benefits and services comparable to their normal functioning peers. As a cornerstone of social integration and mobility, the educational institution has been influential in implementing legislation that supports the acquisitions of these skills for developmentally disabled individuals.

The Evolution of Autism and Present Day Social Impacts

In 1910 Eugen Bleuler, a Swiss psychiatrist, used the term autism to describe a form of schizophrenia characterized by withdrawal (Bleuler 1950). The term autism has its roots in the Greek word “autos” or self. Leo Kanner in the late 1940s published “Autistic Disturbance of Affective Contact.” This paper defined eleven children who
possessed high intelligence, a profound preference for being alone and an “obsessive insistence on the preservation of sameness.” (Kanner 1943).

The 1960s introduced us to the ‘refrigerator mother’ theory as defined by Bruno Bettelheim (Bettelheim 1967). Bruno Bettelheim stated that autism was caused by refrigerator mothers, who were inclined to have maternal coldness toward their children. Parental rejection or “refrigerator mothers” contributed to children exhibiting signs of autism (Bettelheim 1967). The first edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-I) was released in 1952. The DSM-I was a cornerstone of diagnosing mental disorders. The DSM-II, published in 1968, defined 182 various mental disorders. The DSM-I and DSM-II did not list autism as an individual category. Autistic-like symptoms were under the umbrella of childhood schizophrenia.

Treatments for autism were limited in the 1960s, with the drug LSD being occasionally used (Bender, Goldschmidt and Siva 1962). A well-known autism advocate, Temple Grandin, in 1965, developed a “squeeze machine” that produced a substantial calming effect by the application of a deep pressure touch (Grandin 1992).

The Journal of Autism and Developmental Disorders was first published in 1971, with a commitment to autism research. In 1971 the observable differences between autism and schizophrenia were being examined (Kolvin 1971). Established in 1975, the Developmentally Disabled Assistance and Bill of Rights Act (The DD Act) revised the definition of “developmental disability” to include autism. The DD Act also established an arrangement of agencies that were responsible for defending the rights of people with developmental disabilities in the United States.
Autism first appears as a separate category in the DSM-III in 1980. Autism became a part of the social dialogue with the release of “Rain Man” in 1988. The film was vital to the increase of public awareness surrounding autism, although it did not examine autism as having varied behavioral traits. The fourth revision of the DSM-IV in 1994 added several sub-categories to the autism spectrum, including Asperger’s, Rett’s Disorder, Childhood Disintegrative Disorder, and Pervasive Developmental Disorder-Not Otherwise Specified (PDD-NOS).

Between 1998 and 2002, Andrew Wakefield and colleagues published two papers linking the MMR (measles, mumps, and rubella) vaccination to subsequent autism diagnoses (Wakefield et al. 1998). Discredited by other scientists and fully retracted in 2010, these papers have had lasting residual effects with many parents choosing not to vaccinate their children.

The 21st century began with a dramatic increase of autism diagnoses labeled as an “epidemic.” By 2011, the Centers for Disease Control and Prevention reported one in fifty U.S. children as having autism. The DSM-IV, published in 1994, divided diagnostic criteria for ASD into three categories. The three categories included in the DSM-IV were social reciprocity, communicative intent, restricted and repetitive behaviors.

The DSM-V, published in 2013, integrated previously recognized developmental disabilities (Autistic Disorder, Asperger Syndrome, Pervasive Developmental Disorder Not Otherwise Specified, and Disintegrative Disorder) under the umbrella term of ASD. Based on symptoms, currently or by history, new requirements for an autism diagnosis have been rearranged into two areas; 1) social communication/interaction, and 2)
restricted and repetitive behaviors (Hyman 2013). The two areas of diagnosis criteria are based on the levels of support required for those symptoms and reflect the impact of co-occurring specifiers such as cognitive, occupational and physical disabilities.

**Benefits of Early Intervention Services**

Evidence-based research supports the theory that early intervention treatment services can greatly improve a child’s development (Handleman 2000; National Research Council 2001). It is recommended that children begin intervention as soon as they are diagnosed with ASD in order to promote skills that will enable social integration and social mobility. Early intervention is a system of services that helps babies and toddlers with developmental delays or disabilities (http://nichcy.org/babies/overview). Skills that are focused on early behavioral intervention consist of physical, cognitive, communicative, social/emotional, and the establishment of self-sufficiency. Early intervention works to combat developmental delays such as cognitive development, physical development (including vision and hearing), communication development, (social or emotional development), or adaptive development.

Federal regulations have been enacted to provide services for individuals with ASD. The availability of services differs from state to state. The Individuals with Disabilities Education Act (IDEA) says that all children under the age of 3 years (36 months) who are at risk of having developmental delays may be eligible for services (http://nichcy.org/laws/idea). Research supports the importance of early intervention.
However, intervention at any age is beneficial to the individual.
(http://nichcy.org/babies/overview).

Types of Intervention Services

A wide variety of interventions exist for individuals with ASD. Interventions are often relegated into four distinct categories: behavior and communication approaches; dietary approaches; medication; or complementary and alternative medicine. According to reports by the American Academy of Pediatrics and the National Research Council, behavior and communication approaches that help children with ASD are those that provide structure, direction, and organization for the child in addition to family participation (http://www.cdc.gov/ncbddd/autism/treatment.html). “One type of treatment program for a population that exhibits such variability seems ingenuous and is not supported by current empirical evidence” (Sherer and Schreibman 2005:1).

A popular approach to behavior and communication developmental delays is applied behavior analysis (ABA). ABA encourages positive behaviors and discourages negative behaviors in order to improve a variety of skills with the child’s progress being tracked and measured (http://www.cdc.gov/ncbddd/autism/treatment.html). Four main variations of ABA are discrete trial training (DTT), floortime or developmental, individual’s differences, relationship-based approach, pivotal response training (PRT), or verbal behavior intervention (VBI) (http://www.cdc.gov/ncbddd/autism/treatment.html).

Discrete trial training is a style of teaching that uses a series of trials to teach each step of a desired behavior or response. Lessons are broken down into their simplest parts
and positive reinforcement is used to reward correct answers and behaviors. Incorrect answers are ignored (http://www.cdc.gov/ncbddd/autism/treatment.html). Floortime focuses on emotional and relational development (feelings, relationships with caregivers). It also focuses on how the child deals with sights, sounds, and smells (http://www.cdc.gov/ncbddd/autism/treatment.html).

Pivotal response training aims to increase a child’s motivation to learn, monitor his or her own behavior, and initiate communication with others. Positive changes in these behaviors should have widespread effects on other behaviors (http://www.cdc.gov/ncbddd/autism/treatment.html). Verbal behavior intervention is a type of ABA that focuses on teaching verbal skills (http://www.cdc.gov/ncbddd/autism/treatment.html). Other forms of behavior and communication approaches are occupational therapy, sensory integration therapy, speech therapy, and the picture exchange communication system.

Dietary approaches to autism spectrum disorder are not backed by evidence-based research. The removal of particular foods, vitamin, or mineral supplements may reduce certain symptoms of autism spectrum disorders in some individuals (http://www.cdc.gov/ncbddd/autism/treatment.html).

There are currently no medications that exist to treat ASD or the main symptoms. Individuals with ASD may exhibit other disabilities that can be treated with medication, such as high energy levels, inability to focus, depression, or seizures. The uses of complementary and alternative treatments are met with skepticism by traditional medical practitioners. Complementary and alternative treatments may include special diets,
chelation (a treatment to remove heavy metals like lead from the body), biologicals (e.g. secretin), or body-based systems (like deep pressure) (Gupta 2004).

The education system employs a variety of intervention programs. “Once children with ASD enter elementary school, the school becomes the primary service provider, delivering large amounts of special education interventions” (Kasari and Smith 2013:2). Knowledge of the effectiveness of interventions that exist in schools is cursory. Children with autism benefit from an educational system that proactively challenges and strives to diversify teaching pedagogies (Kasari and Smith 2013).

*Availability of Intervention Services*

Specialized medical care is often difficult to access when living in geographically isolated locations. The problem of location and access to services is exacerbated for those with non-traditional disabilities. Evidence-based research supports the hypothesis that early intervention works to promote skills that will enable social integration and social mobility. Parents are typically the first to observe abnormalities in their child’s growth and development. A referral from a medical professional is typically the first step in seeking a diagnosis and subsequent intervention.

This process is often wrought with difficulties and obstacles in the acquisition of a referral. In one study (Smith et al.1994) most parents were referred to another professional after the initial consultation, but more than one-third of the parents surveyed were told either not to worry or to return if the problems persisted. Parents report that the process of receiving services is often complex and unclear. A phone study of 25 families,
examining the experiences of parents/caregivers, revealed that most families interacted with multiple agencies to access services (Kohler 1999). Inflexible work schedules and various other life demands, make it challenging for parents to coordinate and access services with multiple agencies. Problems with services include difficulty accessing services, limited involvement in interventions, and providers engaging in little interagency collaboration. (http://www.cdc.gov/ncbddd/autism/treatment.html).

Counseling services or community-based support groups are ways that parents can be supported while waiting for intervention services to begin. Parents who reside in rural areas are faced with geographic isolation and a lack of community support. Attempting to access services involves large amounts of paperwork and the attendance of multiple meetings in order to access services. Finding ways to streamline paperwork and provide transportation for families and children could help ease one or more of the many daily stressors a parent encounters (Hutton and Caron 2005).
Parental Involvement and Support

The likelihood that children will succeed in the acquisition of social mobility and integration is greatly increased when parents are intimately involved in their cognitive and social/emotional development. Individuals with ASD experience substantial cognitive and social/emotional development when parents are involved in intervention services. As part of the ‘seamless provision of care’ for the child with autism and his or her family, diagnosis should be followed by appropriate early intervention that can bridge the potential gap between an early diagnosis and educational placement (Shields 2001). Early intervention may be child-focused, parent-focused, home-based, or clinic-based (Shields 2001). Parents are more socially integrated into their environment than intervention specialists, therefore parents should develop the tools needed to interact and advocate for their child.

Lack of education often prohibits parents from becoming more involved in intervention services. Parents benefit from home-based programs, as they enable parents to develop a better understanding of strategies and tools utilized in intervention programs. Parental education using single-subject design has been shown to benefit children with autism by increasing children’s non-verbal and verbal communication skills, a reduction of inappropriate behavior, an increase in appropriate play skills, and an improvement in parent-child relationship (Vismara, Colombi and Rogers 2009). An increase in home-based intervention programs aiming to capitalize on working in the child’s natural environment has been observed over recent years (Shields 2001).
Parents of individuals with ASD experience isolation, stress, and frustration. Parents who have familial or community support are better equipped to face challenges that may arise when raising a child with developmental disabilities. Particularly high levels of parental stress are associated with factors outside the family, such as a lack of help and support, as well as with factors relating to the child (Kasari and Sigman 1997). Familial and community-based support is beneficial to families navigating their way through challenges experienced solely by parents of individuals with ASD. An increase in parental confidence is feasible through programs tailored to educating parents. It is vital for training programs to build parental confidence by showing them how their natural parenting skills can cope with the differing needs of their child (Shields 2001).

Conclusion

There is a wealth of literature pertaining to the study of ASD, the social implications of ASD, the availability of intervention services, the benefits of early intervention services, variations of intervention services, and parental involvement and support. Current data concentrates on class and geographical areas. Current and emerging literature would be beneficial to the study of ASD by addressing awareness and importance of services and potential barriers to services.

Individuals with ASD have benefited from the DD Act that aims to protect the rights of U.S. citizens diagnosed with a developmental disability. Early and varied intervention services are instrumental in improving a child’s development. Professional support services empower parents with the tools needed to become effective advocates.
It is advantageous to current and emerging literature to examine research through an intersectional lens.
METHOD

The primary purpose of this study was to determine the levels of importance state mandated supports and services are for Humboldt County parents of individuals with ASD. The secondary purpose of this study was to determine access and barriers parents/caregivers of individuals with ASD experience in Humboldt County. A mixed method approach was utilized to analyze quantitative and qualitative data.

My research questions were: To what extent are individuals with autism spectrum disorder accessing services available to them in Humboldt County? What are the needs of individuals with autism spectrum disorder in Humboldt County? What must be done to overcome barriers to services available to individuals with autism spectrum disorder in Humboldt County?

Surveys and semi-standardized interviews were used to collect data for this study. A self-administered paper-based survey was employed to assess the levels of access, importance of, and barriers to services that parents of individuals with ASD experience in Humboldt County, California. I collaborated with a major, local service provider who agreed to distribute my survey to all its clients (or their parents) who had an ASD diagnosis in Humboldt County, California.

In-depth, confidential, one-on-one interviews with parents, an adult with ASD and service providers of people with ASD provided qualitative data on importance, access, and barriers to services. Participants in the one-on-one interviews were found through the utilization of purposive and snowball sampling. The geographically isolated area and lack
of access to service providers’ confidential client lists made the recruitment of potential interviewees especially challenging.

**Research Design**

This study critically analyzed the experiences parents of individuals in Humboldt County have in accessing services, importance of services, and difficulties in receiving services. This study included an explanatory and exploratory research-based approach. The utilization of an exploratory approach was employed, as the area is not widely researched. My study was cross-sectional, examining different experiences of parents of individuals with ASD at one point in time. This included a self-administered paper-based survey and one-on-one semi-structured interviews.

The survey was dispersed to approximately 177 residents of Humboldt County who were clients of the Redwood Coast Regional Center (RCRC). The survey was mailed once and included a cover letter, survey questionnaire, and a prepaid and stamped return envelope. The cover letter explained the purposes of the study and included informed consent notifications. Surveys were mailed by the RCRC in order to maintain the confidentiality of its clients. As surveys were intended to be returned anonymously, respondents were asked to not include their names or any identifying information. The cover letter instructed respondents to return surveys in the included prepaid and stamped return envelope without including a return address and also explained the study’s purpose.
The surveys consisted of four pages examining the awareness of services, importance of services and difficulty accessing service (Appendix A-1). Demographic information was asked of participants who completed the survey.

The surveys were mailed out on February 6th, 2014, with a return date of February 20th, 2014. Interviews were conducted from February 6th, 2014 through March 15th, 2014. Interviewees also completed surveys and participated in semi-standardized interviews. Interviews were conducted at participants’ residences, local coffee shops, over speakerphone, and at the conference room at the CCRP.

One-on-one semi-structured interviews were held with parents of children diagnosed with ASD and service providers. The interviews were designed to be 60-90 minutes in length. The questions explored their experiences in accessing supports and services in Humboldt County.

**Sampling Plan**

The sampling plan was a nonprobability, purposive sampling technique. Nonprobability sampling was employed for this study as it was not possible to randomly select my sample from the larger population of parents of persons with ASD. The target population I studied is a specific subset of parents who care for someone with a diagnosis of ASD in Humboldt County, California. This population is largely unknown as clients’ identities are protected by confidentially within the organization from which they receive services. Aggregate data sample was gathered though self-administered survey
questionnaires administered to all parents of individuals with ASD who are clients of RCRC.

My interviews were conducted with parents, one adult diagnosed with ASD and service providers. Participants in the one-on-one interviews were found through the utilization of purposive and snowball sampling. Flyers were posted at schools in order to recruit participants. Families Advocating Autism Now (FAAN), an online support group, posted announcements on its online web page to aid in the recruitment of interviewees. The geographically isolated area and lack of access to service providers’ client lists made the recruitment of potential interviewees especially challenging.

Quantitative Analysis

The categories for quantitative analysis were developed from the survey instrument: Awareness, Importance, and Access to Autism Supports & Services. The low percentage of returned surveys does not allow for generalizability of my quantitative based analysis. Data collected from returned surveys were analyzed using SPSS.

Qualitative Analysis

Qualitative data was analyzed through the application of content analysis described by Berg & Latin (2008), Leedy & Ormrod (2005) and Neuendorf (2002) as consisting of a careful, detailed, systematic examination and interpretation of a particular body of material in an effort to identify patterns, themes, biases, and meanings.
Conventional content analysis was employed when analyzing experiences of the participants in regards to access, importance of, and barriers to services of individuals with ASD in Humboldt County. The utilization of latent content analysis allows for me to gain a deeper structural meaning conveyed through the participants’ message (Berg 2009). Data collected from interviews was analyzed using Dedoose.

**Grounded Theory**

Grounded theory was used to analyze the qualitative data in which theories are generated solely from an examination of data rather than being derived deductively (Glaser and Strauss 1967). Grounded theory allows, through the utilization of constant comparative method, for observations to be compared with one another and with the evolving inductive theory (Glaser and Strauss 1967). This inductive approach allows for the data to formulate a new theory better suited to the analysis of the research. Grounded theory is applied to analyze themes that emerge from interviews.

**Operationalization of Concepts and Measurement**

The concepts central to this study were awareness of services, levels of importance, and barriers to services parents/caregivers of individuals with ASD experience in Humboldt County. Concepts central to this study were measured through selected variables.

Operational definitions for this study are:
Awareness of services: Levels of awareness of services was an ordinal variable measured by never heard of it, heard of it, and use them.

Levels of importance: Levels of importance of services was an ordinal variable measured by the extent to which respondents thought services were very important, important, somewhat important, or not important.

Barriers to services: Levels of barriers to services was a nominal variable identified by yes, somewhat, or no.

For purposes of gathering data for this study I developed a structured questionnaire and developed interview questions that followed a semi-standardized format. Variables were measured by employing an index in order to summarize and rank-order specific observations. An index allowed me to generalize my analysis to include the experiences of parents of individuals with ASD residing in Humboldt County.

I employed a variation of Martinek’s (2000:18) instrument that had established validity and reliability of collected survey data.

Human Subjects Protocol

My survey was mass-mailed to approximately 177 residents of Humboldt County. The ages of participants, male to female sex ratio, race/ethnic ratio, socioeconomic status, and health or psychological status varied and was unknown as I did not have access to the RCRC’s client list. All participants who answered the questionnaire were included in the study. The collected material was first-hand data. The material collected was acquired for research purposes and to provide a community needs assessment report to CCRP.
To ensure they were fully aware of possible risks, interview participants were informed that they may experience emotional or psychological trauma. Potential risks to participants have been minimized, including risks to confidentiality, by excluding participants’ names or any other identifying features attached to the interview or survey. A list of support groups and low cost counseling services was provided to each parent/caregiver at the culmination of the interview process.

This study employed a self-administered paper-based survey to collect data which allows for participants to maintain their right to privacy. Confidentiality was ensured by destroying identifying material when it was no longer needed. In this case, one year from the time of the completion of the questionnaire. In order to maintain the confidentiality of interviewees, information derived from interviews and surveys was kept in a locked file cabinet, with the office being locked at all times. I abided by these requirements as defined by the Humboldt State University Institutional Board (approval number 13-073).

To protect or minimize potential risks, including risks to confidentiality, self-sealing envelope were provided to return surveys. Participation in this research study is beneficial to the community in that examines access to services, importance of services, and difficulties to receiving services individuals with autism spectrum disorder experience in Humboldt County, California.
RESULTS

In this section I will cover survey findings, parents of children with ASD and an adult with ASD interview findings, service provider interviews and conclusion.

Survey Findings

Sixteen surveys were completed from the mailing of 177 surveys with a response rate of 11.06%. Nine surveys were completed by interviewees, for a total of 25 completed surveys. Two parents answered for two children each, therefore children’s age and educational attainment were for 27 children out of the 25 respondents. Parents who completed surveys ranged in age from 25 to 66, with a mean of 45.8 years of age. Females completed the majority of surveys at a ratio of 21:4. The current mean age of youth reported by parents was 13.68 years old, with a range of 4-47. The mean age when youth were diagnosed was 5.0 years old. The ratio of diagnosed males to females was 21:6. Parents reported the educational attainment of their youth as ranging between pre-K to some college. Respondents were primarily from Eureka. Other locations are detailed below in Table 1.

Table 1: Cities Respondents resided in.

<table>
<thead>
<tr>
<th>Locations</th>
<th>Percent of Respondents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Eureka</td>
<td>36%</td>
</tr>
<tr>
<td>Ferndale</td>
<td>16%</td>
</tr>
<tr>
<td>Blue Lake</td>
<td>16%</td>
</tr>
<tr>
<td>McKinleyville</td>
<td>12%</td>
</tr>
<tr>
<td>Arcata</td>
<td>8%</td>
</tr>
<tr>
<td>Fortuna</td>
<td>4%</td>
</tr>
</tbody>
</table>
Respondents answered questions that examined their awareness of existing services. Options for answers were “Never Heard of It”, “Heard of It”, and “Use It”.

Table 2 is a list of services that respondents were unaware existed.

Table 2: Top 10 Services that Respondents were unaware existed.

<table>
<thead>
<tr>
<th>Service</th>
<th>Percent of Parents</th>
<th>Number of Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Paid Neighbors</td>
<td>82%</td>
<td>21</td>
</tr>
<tr>
<td>Paid Roommates</td>
<td>72%</td>
<td>18</td>
</tr>
<tr>
<td>Infant Stimulation Services</td>
<td>68%</td>
<td>17</td>
</tr>
<tr>
<td>Homeworker Services</td>
<td>60%</td>
<td>15</td>
</tr>
<tr>
<td>Short-term Out-of Home Care</td>
<td>60%</td>
<td>15</td>
</tr>
<tr>
<td>Sociolegal Services</td>
<td>60%</td>
<td>15</td>
</tr>
<tr>
<td>Follow along Services</td>
<td>56%</td>
<td>14</td>
</tr>
<tr>
<td>Habitation</td>
<td>52%</td>
<td>13</td>
</tr>
<tr>
<td>Support and Sheltered Employment</td>
<td>52%</td>
<td>13</td>
</tr>
<tr>
<td>Assistance in Locating a Home</td>
<td>48%</td>
<td>12</td>
</tr>
</tbody>
</table>

Respondents were asked what services were most important to them. Response options were “Very Important,” “Important,” “Somewhat Important,” and “Not Important.” Table 3 details the top ten services that were most important to respondents.
Table 3: Top 10 Services Most Important to Respondents

<table>
<thead>
<tr>
<th>Service</th>
<th>Percent of Parents</th>
<th>Number of Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Diagnosis</td>
<td>80%</td>
<td>20</td>
</tr>
<tr>
<td>Treatment</td>
<td>80%</td>
<td>20</td>
</tr>
<tr>
<td>Speech Therapy</td>
<td>76%</td>
<td>19</td>
</tr>
<tr>
<td>Education</td>
<td>72%</td>
<td>18</td>
</tr>
<tr>
<td>Evaluation</td>
<td>72%</td>
<td>18</td>
</tr>
<tr>
<td>Respite</td>
<td>68%</td>
<td>17</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>64%</td>
<td>16</td>
</tr>
<tr>
<td>Assessment</td>
<td>60%</td>
<td>15</td>
</tr>
<tr>
<td>Behavior Modification Programs</td>
<td>60%</td>
<td>15</td>
</tr>
<tr>
<td>Behavior Training Programs</td>
<td>60%</td>
<td>15</td>
</tr>
</tbody>
</table>

Respondents answered questions examining which services were difficult or somewhat difficult to access. Options for checking were “Yes,” “Somewhat,” or “No.” Table 4 is a comprehensive list of the top ten services that were difficult or somewhat difficult to access.

Table 4: Top 10 Services that were Difficult or Somewhat Difficult to Access

<table>
<thead>
<tr>
<th>Service</th>
<th>Percent of Parents</th>
<th>Number of Parents</th>
</tr>
</thead>
<tbody>
<tr>
<td>Treatment</td>
<td>60%</td>
<td>15</td>
</tr>
<tr>
<td>Occupational Therapy</td>
<td>44%</td>
<td>11</td>
</tr>
<tr>
<td>Education</td>
<td>44%</td>
<td>11</td>
</tr>
<tr>
<td>Training</td>
<td>40%</td>
<td>10</td>
</tr>
<tr>
<td>Assessment</td>
<td>40%</td>
<td>10</td>
</tr>
<tr>
<td>Evaluation</td>
<td>36%</td>
<td>9</td>
</tr>
<tr>
<td>Referral Services</td>
<td>36%</td>
<td>9</td>
</tr>
<tr>
<td>Mental Health Services</td>
<td>36%</td>
<td>9</td>
</tr>
<tr>
<td>Recreation</td>
<td>32%</td>
<td>8</td>
</tr>
<tr>
<td>Child Care</td>
<td>32%</td>
<td>8</td>
</tr>
</tbody>
</table>

Parent identified themes surrounding unawareness of services, most important services, and services that were difficult to access had a range of 32% to 82%.
Parents, Adult with ASD, and Service Provider Interview Findings

Thirteen interviews were conducted between February 6th and March 15th, 2014. Research based evidence supports the experiences and perspectives of interviewees. Interview responses were examined to evaluate themes that were observed in a review of the literature.

Interviews were semi-structured and 60-90 minutes in length. Nine parents, an adult with ASD, and three service providers who were 18 or older and residents of Humboldt County, CA. The average age of ASD diagnosis as reported by parents was 3.97 years old, the median age was 3 years old, and the range was from 18 months to 19 years of age.

Parents reported levels of developmental delays produced by autism, as ranging from extremely mild to severe. Symptoms associated with autistic delays were either sensory processing delays or low functioning in verbal communication. Parents reported the severity of ASD delays in Table 5.

Table 5: ASD Severity as Reported by Parents

<table>
<thead>
<tr>
<th>Severity of Developmental Delay</th>
<th>Number of children</th>
</tr>
</thead>
<tbody>
<tr>
<td>High Functioning</td>
<td>5</td>
</tr>
<tr>
<td>Autistic</td>
<td>3</td>
</tr>
<tr>
<td>Mild to Severe</td>
<td>1</td>
</tr>
<tr>
<td>Unidentified</td>
<td>1</td>
</tr>
</tbody>
</table>

Parents described symptoms of high functioning ASD that they observed as being: difficulty in making eye contact with others, needing structure to focus, and
delayed speech. Individuals with delays not specifically linked to ASD symptoms are labeled as autistic. One interviewee reported her child’s initial diagnosis:

“(His) original diagnosis was PDD or Pervasive Developmental Disorder. (He) is now under the autism umbrella.”

Another parent described the benefits of her child being labeled as autistic:

“(His) original diagnosis was mental retardation. (He) was later labeled as autistic and has started receiving services from RCRC.”

One child’s delays were reported as being mild to severe on the autism spectrum. For example:

“(His) communication and verbal disabilities are severe. (His) problem solving is super gifted. So (he) is on two ends of the spectrum. (He) kind of falls just below the midways level of the spectrum.”

A numbers of codes and sub-codes emerged during the qualitative analysis of parents, adult with ASD, and service provider interviews. Findings that emerged throughout the analysis process revealed that perspectives and experiences of interviewees were both static and fluid. Grounded theory was employed in the analysis of interviews (Charmaz 2006).

Table 6 is a detailed list of primary codes developed by an analysis of parent identified themes. Following the table is a discussion of these codes and sub-codes.
Table 6: Primary Codes observed in Interview Findings

<table>
<thead>
<tr>
<th>Developmental Delays</th>
</tr>
</thead>
<tbody>
<tr>
<td>Services</td>
</tr>
<tr>
<td>Barriers to Services</td>
</tr>
</tbody>
</table>

Developmental Delays.

Developmental delays, defined by the CDC (http://www.cdc.gov/ncbddd/autism/signs.html), commonly observed in individuals with ASD are located in the table below. Although not all of the interviewees have observed all of these developmental delays, they have observed many of these developmental delays in their children.

Table 7: Developmental Delays associated with ASD

<table>
<thead>
<tr>
<th>Communication</th>
</tr>
</thead>
<tbody>
<tr>
<td>Social Interaction</td>
</tr>
<tr>
<td>Behaviors</td>
</tr>
<tr>
<td>Sensory Integration</td>
</tr>
<tr>
<td>Measured Intelligence</td>
</tr>
<tr>
<td>Motor Delays</td>
</tr>
</tbody>
</table>

Developmental Delays. Communication. Communication was discussed by parents as the ability to use words correctly. Interviewees discussed obstacles their child or they faced based on the inability to communicate on the same level as their peers. The inability to effectively communicate one’s feelings may impact social interaction. One
parent discussed how the inability to effectively communicate impacted the child’s ability to socially interact:

“(My child) experienced delayed speech, was not mimicking, didn’t understand verbal queues, and wasn’t speaking or using words the way peers his age were.”

Social interaction delays based on the inability to effectively communicate may result in an individual becoming violent or exhibiting aggressive behavior. One adult with ASD shared that emotional frustration to effectively communicate was relieved through aggressive behavior:

“(I feel) that using people’s names feels too powerful and gross. (I experience) physical rage due to an inability to communicate emotions.”

Lastly, communication and social interaction delays can potentially benefit from verbal behavior intervention (a type of ABA that focuses on teaching verbal skills [http://www.cdc.gov/ncbddd/autism/treatment.html](http://www.cdc.gov/ncbddd/autism/treatment.html)). This form of intervention may improve the communication delays described by this parent:

“Before diagnosis she wasn’t talking. (She) didn’t understand anything that we said, only communicated through tantrums.”

**Developmental Delays. Social interaction.** Social interaction was described by parents as the inability to make eye contact or enjoy interaction with other people. The inability to initiate or maintain eye contact are obstacles to the development of friendships and relationships for those who experience social interaction delays. Children with ASD
are often misunderstood by their peers based on their abnormal ways of engaging in play. Youth may parallel play or play beside their peer, as opposed to playing with them. Youth are also observed playing by themselves and not with their peers. Teachers or child care providers may view these children as displaying exemplary behavior, since they are not disruptive in a classroom setting.

The education system, as the primary service provider for school age youth, provides youth with ASD the opportunities to learn social skills. One parent discussed how intervention worked to minimize symptoms associated with social interaction delays:

“(He) didn’t tell us when he was fatigued or emotionally upset, because he didn’t know how. (My child) wondered how he would be perceived.”

One adult with ASD reported how their social interaction with peers or co-workers was impacted by their inability to make eye contact. Management and fellow co-workers viewed this person as being weird or unprofessional as a result of this.

Developmental Delays. Behaviors. Behaviors were discussed by parents as a variation of repetitive behaviors (i.e. hand flapping, obsessive interests, or lining up toys or other objects). Individuals with ASD may experience obstacles to social integration, based on the inability to self-regulate behaviors. Outside family and community members may be bewildered by the behaviors of individuals. This lack of understanding is observed in the isolation families experience when attempting to engage in social interactions.
Autism awareness is beneficial to all community members, as it takes away the mysticism of symptoms associated with developmental disabilities. Families of individuals with ASD benefit from family and community support, when faced with the daunting task of helping their child learn to self-regulate behaviors. One parent described ways in which her child was unable to self-regulate behaviors:

“(My child) used to bite or pull hair. (My child) was unable to watch age appropriate television shows as they would make him become more violent.”

The inability to self-regulate behaviors may be a side effect of sensory integration difficulties. One parent described techniques used to stabilize disruptive actions:

“(The texture) of sand or a bowl of rice is soothing.”

Behaviors are not necessarily violent in nature. Behaviors may also manifest in the inability to understand personal space and keeping their hands to themselves. A parent discussed prior challenges their child experienced in wanting to be physically close to his peers. This disruptive behavior recounted how their child’s prior challenges of wanting to be physically close to his peers was disruptive in a class setting:

“(Child) is currently working on keeping their hands to their self. (Child) is working on sitting still.”

This demonstrates how it is not an easy or quick fix but an ongoing and long term behavior modification process.
Developmental Delays. Sensory Integration. Sensory integration difficulties were discussed by parents as the ways in which their children respond to touch, smell, sound, taste, and feel. Sensory processing difficulties limit the amount and types of outings families are able to experience. Some individuals with ASD find everyday life especially challenging, based on the inability to process sensory signals. Difficulties with processing signals also impact family outings. Sensory integration difficulties may mentally paralyze an individual. A parent reported sensory difficulties that they observed in their child’s behaviors:

“(My child) has a heightened sense of awareness to sound, smells, and sensitivity to certain textures.”

Parents may feel frustrated as they are not able to control or help their child learn how to cope with anger or sadness that occur with sensory integration issues.

Sensory integration difficulties are also obstacles to parents as a result of consistency in sensory delays. Parents will adapt to their child’s sensory problems, only to have them change. In order to maintain some sense of control, children may engage in a variety of unusual behaviors. A parent described the ways their child attempted to maintain control of self by feigning helplessness:

“(My child) had a lot of sensory issues. In order to feel safe (she) wanted to be picked up a lot. (She) needed help putting on her shoes, even though she knew how to.”
Developmental Delays. Measured Intelligence and Motor Delays.

Measured intelligence was described by parents as a range of intelligence ranging from intellectually disabled to gifted. Measured intelligence is not a reflection of an individual’s ability to communicate. Measured intelligence is indicative of individual’s cognitive abilities. Necessary services and supports that are allocated by local service organizations, are often based on the severity of an individual’s delays. Measured intelligence can either improve or regress. One parent reported how their child’s measured intelligence had improved:

“(My child’s) original diagnosis was mental retardation. (He) was later diagnosed as being autistic by a school psychiatrist.”

On the opposite end of the spectrum, one parent reported how their child’s measured intelligence had regressed:

“(My child) had a great memory. She had a fascination with letters at an early age, learned to identify letters early. However, (she) wasn’t putting two words together at two, (she) was using baby sign language.”

Motor delays were described by parents as the attainment of gross motor or fine motor skills that enable us to learn how to walk or use fingers to grasp small items. Motor delays impact communication and occupational skills. Parents described how the inability to master motor skills was a barrier to educational and occupational development. One parent recounted how their child’s education was impacted by challenges with mastering fine motor skills:
“(She) was having trouble with fine motor skills, such as drawing a circle or coloring.”

Another parent discussed how their child wasn’t developing like normal functioning peers:

“(She) couldn’t do anything her peers could, (brush her teeth, eat her snack).”

Services.

This section explores the complexity of experiences parents reported when attempting to access services. Major themes that emerged from interview findings were: parental processes of accessing services, parental satisfaction with services, effectiveness of services, and barriers to services.

Access to services. Straightforward. Some parents reported attempts at accessing services as being straightforward. The ability to access services without obstacles is beneficial to those with ASD, as it allows them to access intervention services without delay. Parents felt empowered when accessing services is quick and case managers are readily accessible.

Access to services. Referral for Evaluation. Some parents reported that the process of receiving a referral for an evaluation of their child’s delays was relatively simple, with little to no barriers.
One parent expressed a sense of relief at how simple it was to obtain a referral for an evaluation:

“The doctor and I went over 2 questionnaires to assess (his) cognition and physical aptitude. (We) were referred to the Regional Center, (the child) was tested there; (We) went to the speech pathologist 3 times. (We) had visits with a behavioral therapist 3 times.”

Medical professionals, who are aware of the symptoms associated with ASD, decrease the amount of time parents may experience when waiting for an initial evaluation. One parent discussed their experience with me:

“(We) went to a local doctor and told the doctor that we suspected that something wasn’t right. Doctor noticed that the child wasn’t making eye contact, gave a referral to RCRC, went to RCRC, had an interview with them, went to a child psychologist for 3 days, she observed them at home, last day someone came in from RCRC; told us about the PALS class; signed her up for Headstart, went into the RCRC to talk to them about services.”

In addition, preschool and early education teachers may discuss their concerns with parents over a child’s developmental disability. For example:

“Our (child) was: referred by preschool teacher; she thought he may need to be tested; evaluations done through the RCRC; diagnosed with ASD.”

Upon the receipt of an ASD diagnosis, family’s schedules and lives are altered to accommodate for intervention services. Therapy or intervention services are scheduled
around the family schedules. Therefore, services may occur during the evening hours or on the weekends.

**Access to services. Lengthy.** On the opposite end of the spectrum, some parents faced challenging roadblocks when attempting to access specialized education services. Specialized education is influential in the social and educational integration of children with ASD into mainstream society. Specialized education incorporates the improvement of developmental delays in its curriculum ([http://www.humboldt.k12.ca.us/special-beginnings.php](http://www.humboldt.k12.ca.us/special-beginnings.php)). Parents reflected on the ways in which attending special day classes prepared their child for the life/social skills necessary in a traditional classroom setting. In order for a child to be admitted into a special day class, an IPP or IFSP must be in place to formulate an Individualized Education Program (IEP). An IPP (a list of goals, services, and supports) is instrumental in a child learning necessary life, social, and educational skill. As defined by the state of Nebraska, an Individual Family Service Plan (IFSP) is both a process and a document intended to assist families and professionals in a community in their combined efforts to meet the developmental needs of a young child from birth to age three with special need ([http://ifspweb.org/index2.html](http://ifspweb.org/index2.html)). An IEP includes certain information about the child and an educational program that is designed to meet his or her unique needs [http://www.ncld.org/students-disabilities/iep-504-plan/what-is-iep](http://www.ncld.org/students-disabilities/iep-504-plan/what-is-iep). Topics that may be included in an IEP are current performance, annual goals, special education and related services, accommodations, participation in state and district-wide
tests, needed transition services and measured progress (http://www.ncld.org/students-disabilities/iep-504-plan/what-is-iep). Clients were not able to quickly access services due to service providers not initiating an IPP or IFSP. One parent said:

“(We) spoke to the head of a local pre-school and were told we needed an IEP in order to get our child into the special day class. We were then told there was no room in the special day class. At the IEP meeting people from HCOE, Eureka City schools, special education, RCRC and Head Start were in attendance. (We) felt intimidated being in a room full of professionals. After subsequent challenges to place our child into a special class, we sued the local public system. The school system was forced to make room for (our child).”

Access to services. Native Support & Advocacy. Native communities are faced with additional challenges to accessing services. Intervention services and therapy for people with ASD are increasing, yet still limited. Marginalized Native American communities, parents who were relocated to reservations and their children to boarding schools, are now in competition for intervention services with their white neighbors. Culturally sensitive service providers/coordinators are influential in teaching parents how to advocate for the rights of Native American youth. One Native American parent told me:

“(It was a) lengthy process; a number of tests were done; lot of tests with psychologist; about a year long process. A coordinator taught me how to be an advocate in order to access services.”
Native American parents are empowered to face obstacles that prevent accessible services, through knowledge of their child’s legal rights.

Satisfaction with services: Some parents satisfied with accessibility of services. Some parents reported a variety of experiences when meeting with case workers during the initial intake. Parents discussed how quickly case workers distributed resources when parents were knowledgeable of available services. Prior knowledge of Section 504 of the Rehabilitation Act of 1973 and Title II of the Americans with Disabilities Act (ADA), empowers parents to request additional benefits and services needed to improve developmental delays. One parent reported their experience working with the school system as being positive:

“After the diagnosis, (he) was entered into the special day class. The kindergarten IEP was great. The school staff was very supportive and willing to work with us.”

Another parent recounted how their knowledge of services was influential in the acquisition of scant resources:

“(The) School and the principal (were) contracting with an assistant (to) help son transition.”

Whether or not parents had prior information about resources impacted the amount of time it took to access services. Identified intervention services were readily available as a result of key informants providing insider knowledge. Additional
supports, within the school setting, reduce the likelihood of a child experiencing academic challenges.

Satisfaction with services: Effectiveness of services. Intervention services are most effective the earlier a child can begin therapy. Parents who had minimal challenges to accessing services were more likely to receive additional services as opposed to parents who did not share the same experience. Youth received supplementary tools needed to become independent and self-reliant. For example:

“Behavioral therapist outsourced through the RCRC came to the home and worked on life skills such as (potty training).”

Another parent confirmed the positive effects of supplementary services:

“Behavioral services, initial services, tools to work with son to help him succeed; organization worked with parents at home and with the preschool.”

Dissatisfaction with services. Some parents dissatisfied with accessibility of services. Some parents described ways in which services were not as readily available to them as a result of economic capital. Higher economic capital may be a hindrance to accessing intervention services. There is the assumption that families with more economic capital can afford to access services more readily. One parent described the frustration they felt in not being able to enroll their child in a program that would address the child’s delays:
“(We don’t) qualify for head start, due to higher income level. Being in a higher income bracket limits the services (we) would like to access, such as Head Start.”

Programs tailored toward children with ASD ensure parents that their child is being taught emotional, social, and academic skills. Families with high economic status may be excluded from programs that would improve their child’s developmental delays; as they are expected to be able to obtain similar services elsewhere.

Parents dissatisfied with accessibility of services. Lack of one-on-one aides. One-on-one aides, in a preschool or school setting, are influential in assisting youth with ASD increase social and educational progress. Parents who aren’t provided with professional assistance, often take on the dual role of service provider. Parents, faced with the possibility that their child may developmentally regress, may feel frustration or anger.

In the parent’s words:

“Head Start wasn’t working out. (The) parent had to be in the class with the child. The IEP meeting went bad, there was fighting and arguing.”

Service providers dissatisfied with accessibility of services. Denial of education.

Service providers gave examples of Section 504 of the Rehabilitation Act of 1973 being directly or indirectly disregarded within local schools. Youth with autism socially and academically develop when placed in an environment with typical peers. One service provider stated:
“(Teachers would say) I don’t know how to teach a child like that (referencing a child with developmental disabilities).”

Youth with ASD thrive in a structured environment. Schedules are carefully designed so that youth are empowered with a sense of control that they otherwise do not have. A service provider told me how students were being excluded from traditional classrooms:

“Students were told they were late to class and sent back to their special day class.”

In order for ASD youth to learn the same developmental skills as their typical peers, they are mainstreamed into regular classrooms. Youth that are denied access to regular classrooms, are challenged with learning age appropriate developmental skills and behaviors.

Youth with ASD benefit from behavioral intervention, so that they may learn how to self-soothe or self-regulate their emotions. Support service providers, also advocates for youth and parents, reported being excluded from meetings addressing potential services a child may need. In order to receive services for delays, youth must meet criteria of tests designed to determine if a child has is challenged developmentally and to what degree.

One service provider discussed how youth with special needs were being discriminated against:

“(I observed) youth not receiving tests that would provide proof that they had a developmental disability”
**Barriers:**

Barriers were experienced and discussed by nearly all interviewees. Their comments fall into the subcategories of Native American experiences, referrals for evaluation, limited funding, and parents’ dissatisfied with accessibility of services.

**Barriers. Native Americans.** Native American communities, in particular, are impacted by position and resource scarcity in higher amounts than other minority groups (Kivisto 2008). One Native American parent that I spoke with stated that Native youth with developmental delays were being denied access to services. As reported in the Two Rivers Tribune by Korns (2014), “185 students, or approximately 18% of the Klamath-Trinity Joint Unified School District (KTJUSD) student population, are classified as needing some form of special education.” As a result of prior trauma and exploitation, for example the forced removal of Native American children from their families to white-run boarding schools from approximately the 1880s to the 1930s and later, (http://www.sagchip.org/ziibiwing/planyourvisit/pdf/aibscurrguide.pdf) local tribes were hesitant to work with the local school system. One parent proposed that Native councils study how youth were being impacted by a lack of collaboration. For example:

“*(There are) No bylaws protecting children with disabilities; (The) council should be working with the schools more, (we need) more community support.*”

Parents also stated that residing in remote areas restricted access to respite and intervention services. This interviewee stated:
“Respite workers are difficult to locate that are trustworthy and have worked with a child with autism; geographical isolation makes it difficult to access services.”

Geographical location was also observed to effect reliable and sufficient workers. Youth received substandard services as workers had a large caseload of clients to attend to. Living on reservations, away from resources, has added additional challenges to accessing services for Native Americans. A parent stated:

“Services are not static, (they) come and go; speech therapy (1 for 3-4 other schools); not enough behaviorists or occupational therapists for the area. (There is a lack of) one on one aides in schools.”

Barriers. Referral for Evaluation. Parents reported medical professionals invalidating parents’ concerns in regards to their child’s developmental delays. Professionals told parents that children develop at their own pace and would catch up to their peers. Children with ASD may regress developmentally due to a number of reasons. One parent described how challenges in acquiring referrals impacted their child’s development:

“The doctor did not believe (my) initial concerns during checkups. (I) was told (she) would grow out of lack to progress in the same manner as her peers. (Her) learned behaviors began to regress. We finally were able to receive a diagnosis of ASD. (I) felt relieved that my concerns had finally been confirmed.
An adult with ASD discussed their reluctance to access services, based on an evaluation with a skeptical medical professional:

“The process was difficult, due to not being taken seriously. (I) found that only professional opinions were valid.”

**Barriers. Limited funding.** Service providers are challenged with a decrease in funding as the number of diagnosed people is on the rise. In order to decrease the funding of supports and services, parents are asked what services they need. It is possible that families are not asking for needed services that are available to them due to lack of awareness of available services. This lack of knowledge is advantageous for service organizations, as they retain limited funds. In one parent’s words:

“(During the) first interview with case manager, first thing they say is we don’t have any money, your child is on a waiting list, what do you want for your child. (I’m) thinking aren’t you supposed to be telling me what is offered. You’re asking me what I want, I don’t even know, what does a child with autism need, how do we get her in this PALS class, what would you want if we did get money.”

**Barriers. Parents dissatisfied with accessibility of services.** Parents may be allotted a certain number of respite hours a month, based on the services and supports needed for their child with ASD. Respite workers who are consistently unreliable, control whether parents can utilize respite hours. Youth who are used to a predictable schedule may
experience delays to progress, as a result of structural changes. One parent in particular stated:

“Caseworker changed several times; people don’t want to do it; the hours we have allotted, we can’t use, we’ll get ready to do something, they’ll flake off and leave; behaviorists are often students and they leave.”

Respite workers are aware that clients may developmentally regress due to unexpected changes in their routine. A service provider stated their observations of unreliable respite workers:

“Respite workers often quit or miss scheduled respite services. Clients are upset, because they get used to their worker coming at a certain time.”

Conclusion

This chapter analyzed survey findings and interview findings with parents, an adult with ASD, and service providers. This presentation of findings has provided the needed information to answer my research questions. My research questions are listed and answered below.

**To what extent are individuals with ASD accessing services available to them in Humboldt County?**

A range of experiences were reported among parents of individuals with ASD attempting to access services. Research-backed evidence supports that access to early intervention services can greatly improve a child’s ability to overcome developmental
delays. The top 3 services that respondents were unaware existed were: Paid Neighbors (82%), Paid Roommates (72%), and Infant Stimulation (68%). Three services that were most important to respondents were: Diagnosis (80%), Treatment (80%), and Speech Therapy (76%). Services that were reported as being difficult or somewhat difficult to access were: Treatment (60%), Occupational Therapy (44%), and Education (44%).

*What are the needs of individuals with autism spectrum disorder in Humboldt County?*

The needs of individuals with ASD in Humboldt County are not predictable, as symptoms of developmental delays vary from person to person. Individuals in Humboldt County utilized diagnosis, treatment, and speech therapy to improve developmental delays. Parents expressed the desire to have intervention services readily available and dependable.

*What must be done to overcome barriers to services available to individuals with autism spectrum disorder in Humboldt County?*

Parents reported several processes that could be engaged in to overcome barriers to services. A summarization of these suggestions are as follows. An assortment of support groups and low to no cost mental health therapy is needed to address the mental and emotional needs of parents/caregivers of youth with ASD. Native American communities may potentially need additional mental health services, to address historical based trauma experienced during the era of boarding schools, in
order to build trust of government agencies so that services may be accessed. Respite workers need to be readily available, dependable, and qualified to work with clients with ASD. Respite workers, living in isolated areas, can potentially be cross trained to provide services to residents with ASD. A reduction in community-based stigma of individuals with ASD of all racial and ethnic groups is needed and can be addressed through autism awareness education. An examination of available funding, and how it is dispersed, can be reviewed to determine if any discriminatory or biased relegation of funds are observed.
DISCUSSION

This final chapter is a summarization of survey and interview findings. Conflict theory is employed to analyze themes that emerged from survey and interview findings. Emergent themes were quantitatively and qualitatively analyzed. A review of the literature confirms the need for access, importance and barriers to services in Humboldt County, CA. In conclusion, recommendations are made addressing the needs of people with ASD.

Quantitative Summary.

Self-administered surveys were mailed to 177 RCRC’s ASD client. Survey respondents reported the top 3 services they were unaware existed as being Paid Neighbors, Paid Roommates, and Infant Stimulation Services. The top 3 services that were very important to respondents were identified as: Diagnosis, Treatment, and Speech Therapy. The top 3 services reported by respondents as being difficult or somewhat difficult to access are: Treatment, Occupational Therapy, and Education.

With a response rate of 11 %, it is not possible to make a generalization of the ASD community in Humboldt County, CA. The possibility that services might be reduced if clients participated in the survey, may have caused a low response rate. Additionally, clients may have suspected their personal information would be viewed by services providers, which could have contributed to a low survey response rate.
Finally, the survey’s association with Humboldt State University and a major service provider, may have contributed to a low response rate.

Qualitative Summary.

Thirteen interviews conducted with parents, an adult with ASD and service providers, recruited through purposive and snowball sampling. These interviews examined themes observed in a review of the literature. Themes that emerged from parents, an adult with ASD, and service provider interviews were access, satisfaction with, dissatisfaction with, and barriers to services. Service providers are less likely to intervene or challenge observed discrimination of youth with ASD, due to having a lower authoritative status than organizations.

Interview findings corroborated sub-themes observed in a review of the literature: importance of early diagnosis, early intervention, availability of services and adequate parental supports. Respondents living in more populated areas of Humboldt County (88.0%), are less likely to experience barriers to accessing services than those living in less populated communities (Loleta, Willow Creek, and Fortuna). As observed in Kivisto (2008:226), residents of smaller communities are competing for resources with residents of larger communities.

Parents facing minimal obstacles to accessing services are more likely to receive and identify resources. Collaboration between parents and service providers enables parents to make informed choices regarding services. Shields addresses the benefits of early diagnosis and subsequent academic achievement by stating, “the
‘seamless provision of care’ for the child with autism and his or her family, diagnosis should be followed by appropriate early intervention that can bridge the potential gap between an early diagnosis and educational placement.” (2001:49).

Individuals with ASD experience substantial cognitive and social/emotional development when parents are involved in intervention services. In order to educate parents about various intervention therapies, it would be prudent to make them members of the therapy team. The team approach is preferred as it eliminates the power service providers have over parents. Being directly involved, in interventions that improve their child’s developmental delays, allows parents to experience their child’s challenges and successes (Vismara, Colombi and Rogers 2009).

As noted in a review of the literature, evidence-based research supports the hypothesis that early intervention works to promote skills that will enable social integration and social mobility. Parents interviewed described the cognitive, communicative, social/emotional, and self-sufficiency benefits they observed as a result of early intervention. With a response rate of 11%, findings are not able to be generalizable to clients of RCRC. Medical professionals report that intervention is most effective before the age of 4. The mean age of diagnosis in Humboldt County was 5 years old. Due to the remote location of Humboldt County, 1 year above the recommended age of 4 can be viewed as acceptable.

Parents reported a variety of barriers to accessing services. Living in a rural area impacted the available funding, number of knowledgeable medical professionals,
existence of un-reliable service workers, and presence of bigotry toward Native Americans.

Parents described resistance from doctors when attempting to obtain a referral for an evaluation. Parents were told that their child would progress at their own speed, while establishing that the professionals knew better than parents’ concerns. Doctors occupy a higher socio-economic status than a majority of Humboldt County’s population, with those specializing in developmental delays possessing more socio-economic status than their peers. Native Americans face challenges that no other racial/ethnic group encounters in Humboldt County. The move west by Anglo-Americans resulted in the cultural and physical genocide of Native Americans. Those who weren’t victims of physical genocide were forced onto reservations, with their children being placed in boarding schools. Descendants of original settlers still reside in the area, wielding economic and legislative power over Native communities.

Recommendations.

The needs of members of the ASD community are seemingly simple, yet complex. Interview findings report that there is a need for easily accessible services, qualified and dependable respite workers, a school system that is knowledgeable of current legislation protecting youth with developmental disabilities, and community inclusion. It is unknown if parents found services to be effective when attempting to improve their children’s developmental delays.
Inclusion into the community may be implemented by members of the community educating themselves on what ASD looks like. Fear of symptoms associated with ASD isolate families of people with ASD. Family and community-based support is beneficial to families navigating their way through challenges experienced solely by parents of individuals with ASD.

Knowledge of available services and how to obtain them should be taught in classes geared toward parents and adults with ASD. Potential classes should focus on legal rights, how to be prepared for an IEP or IFSP, how to advocate for their youth, and ways to access needed supports and services mandated by the state of California. The lack of education surrounding awareness of autism needs to be addressed on a regional level. Counseling services or community-based support groups are ways that parents can be supported while waiting for intervention services to begin.

The intent of this project was to design a template for future needs assessments focusing on the lives of people with ASD residing in rural areas.
REFERENCES

American Indian Boarding Schools: An Exploration of Global Ethnic & Cultural Cleansing.


(Retrieved Friday April 18, 2014)


Public Law 106-402; 106th Congress.


Appendix A1: Letter to Parents/Caregivers

Michelle Showers, Masters Student  
Humboldt State University  
1 Harpst Street, Arcata, CA 95521  
(707) 826-3427

Dear Parent/Caregiver:  

February 2014

Over the past year and a half, I have wondered what parent/caregivers experiences have been when trying to access services and potential barriers to accessing services they may have encountered. As the parent of a child with autism spectrum disorder I have found that accessing services has at times been challenging. I am interested in learning about other parent/caregivers experiences in accessing and knowledge of available services. I am currently completing my Master of Arts degree in Sociology at Humboldt State University, Arcata, CA. My Masters project will be an examination of access and awareness to state mandated services that individuals with autism spectrum disorder may encounter in Humboldt County, CA. I will also be examining parents/caregivers awareness of available services, how important these services are to parents, and the level of difficulty they have experienced in accessing services. It is my intention that my research project will inform local service providers of how important services are to parents/caregivers, their levels of awareness of these services, and whether they have experienced any difficulty receiving services.

This survey will take approximately 20 minutes to complete. I appreciate your willingness to help me with this research project. This project will inform local service providers of how important services are to parents/caregivers, their levels of awareness of these services, and whether they have experienced any difficulty receiving services. The information gathered from this survey will be presented in a summary report to service providers and community at large to hopefully help improve access and knowledge of services. The summary report will be available in June 2014 at The CCRP’s website at http://www.humboldt.edu/ccrp or you may personally call me, Michelle Showers at (707) 826-3427 to obtain a copy. Dr. Christina Martinek is the Humboldt State University faculty supervising this project and she may be contacted at Humboldt State University, 1 Harpst Street, Arcata, CA 95521, and (707) 826-4445 or cam30@humboldt.edu, If you have any concerns with this study, contact Dr. Ethan Gahtan at eg51@humboldt.edu or Dr. Rhea Williamson at Rhea.Williamson@humboldt.edu.

Your participation in this survey is completely voluntary. Completion of this survey is intended to be anonymous. Therefore, please do not write your name on the survey. Please return the questionnaire in the attached self-addressed stamped envelope by February 20, 2014. The provided envelope will be mailed directly to me in order to
ensure that I will be only one to see your responses. Your participation in this questionnaire will establish **Informed Consent** as upheld by Humboldt State University; in other words you agree that any information received may be used in my Masters Project, professional presentations, and future publications.

It is essential that you return this questionnaire by February 20, 2014. You may contact me at (707) 826-3427, if you have any questions or comments. Thank you for your time and concern.

Sincerely,

Michelle Showers, Masters Student
Department of Sociology, Humboldt State University

I have read and understand the information provided and agree to participate in the following study.

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<thead>
<tr>
<th>Print Name</th>
<th>Date</th>
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**Sign Name**
Appendix A2: Awareness, Importance, and Access Autism Supports & Services

Thank you for taking the time to complete this survey. The survey should take approximately 20 minutes to complete. As the parent of a child with autism spectrum disorder, I feel it is important that local service providers are aware of the how important services are to parents/caregivers, their levels of awareness of these services, and whether they have experienced any difficulty receiving services.

This survey is completely voluntary. This survey will preserve the confidentiality of your answers to the questions. Please feel free to leave any questions blank that you do not wish to answer. However, answering all the questions will allow me to do a more complete report. If you have any questions/comment about this survey, please contact me, Michelle Showers at (707) 826-3427 or mms818@humboldt.edu.

The following is a list of Services and Supports for Persons with Developmental Disabilities as Mandated by the Lanterman Developmental Disabilities Services Act and Related Laws, Division 4.5, section 4512 (b) for California Residents. Please tell me whether you are aware of these services, how important these services are to you as the parent/caregiver of an individual with autism spectrum disorder, and if you have any difficulties in receiving these services.

<table>
<thead>
<tr>
<th>Are you aware of these services?</th>
<th>Services</th>
<th>How important are these services to you?</th>
<th>Have you had any difficulty accessing this service?</th>
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<tbody>
<tr>
<td>Never heard of it</td>
<td>Diagnosis</td>
<td>Very important</td>
<td>Yes</td>
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<td>Heard of it</td>
<td>Evaluation</td>
<td>Important</td>
<td>Somewhat</td>
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<td>Use them</td>
<td>Treatment</td>
<td>Somewhat important</td>
<td>No</td>
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<td></td>
<td>Personal Care</td>
<td>Not important</td>
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<td>Day Care</td>
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<td>Domiciliary Care</td>
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<td>Special living arrangements</td>
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<td>Physical Therapy</td>
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<td>Occupational Therapy</td>
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<td>Speech Therapy</td>
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<td>Supported &amp; Sheltered Employment</td>
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<td>Mental Health Services</td>
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<td>Services</td>
<td>How important are these services to you?</td>
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<td>Never heard of it</td>
<td>Recreation</td>
<td>Very important</td>
<td>Yes</td>
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<tr>
<td>Heard of it</td>
<td>Counseling of the individual with a developmental disability &amp; of his/her family</td>
<td>Important</td>
<td>Somewhat</td>
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<td>Use them</td>
<td>Protective services</td>
<td>Somewhat important</td>
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<td>Social Services</td>
<td>Not important</td>
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<td>Sociolegal Services</td>
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<td>Information Services</td>
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<td>Referral Services</td>
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<td>Follow-along Services</td>
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<td>Adaptive Equipment</td>
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<td>Adaptive Supplies</td>
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<td>Advocacy Assistance</td>
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<td>-Self-advocacy Training</td>
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<td>-Peer Advocates</td>
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<td>Assessment</td>
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<td>Assistance in Locating a Home</td>
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<td>Child Care</td>
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<td>Behavior Training Programs</td>
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<td>Community Integration Services</td>
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<td>Community Support</td>
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<td>Daily Living Skills Training</td>
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<td>Emergency and Crisis Intervention</td>
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<td>Facilitating Circles of Support</td>
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<td>Habilitation</td>
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<td>Homemaker Services</td>
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<td>Infant Stimulation Programs</td>
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<td>Are you aware of these services?</td>
<td>Services</td>
<td>How important are these services to you?</td>
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<td>Never heard of it</td>
<td>Paid Roommates</td>
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<td>Heard of it</td>
<td>Paid Neighbors</td>
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<td>Use them</td>
<td>Respite</td>
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<td>Short-term Out-of home Care</td>
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<td>Social Skills Training</td>
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<td>Specialized Medical and Dental Care</td>
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<td>Supported Living Arrangements</td>
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<td>Training for Parents of Children with Developmental Disabilities</td>
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<td>Training for Parents with Developmental Disabilities</td>
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<td>Vouchers</td>
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<td>Transportation Services Necessary to Ensure Delivery of Services to Persons with Developmental Disabilities</td>
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</table>
In the following questions I am interested in getting an idea about the people I am surveying. Please fill out the following information:

How old are you? ______ years
What is your gender? ______________
Age of individual with Autism Spectrum Disorder? ______ years
Age individual was diagnosed with Autism Spectrum Disorder? ______
Gender of individual with Autism Spectrum Disorder? ______________
What town do you live in? __________
What is current educational level of the individual with Autism Spectrum Disorder? (circle one)
Pre-K                                          Seventh Grade              Some College
Kindergarten                                   Eighth Grade               Associate Degree
First Grade                                    Ninth Grade                Bachelor’s Degree
Second Grade                                   Tenth Grade                Graduate Degree
Third Grade                                    Eleventh Grade
Fourth Grade                                   Twelfth Grade
Fifth Grade                                    High School Graduate/GED
Sixth Grade

If you have any additional comments please write them below:

____________________________________________________________________________________
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____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________
____________________________________________________________________________________

Thank you again for helping with this study.
Please return this survey by **February 20, 2014** to:
Michelle Showers, Sociology Masters Student, Humboldt State University (CCRP),
1 Harpst Street, Arcata, CA 95521
(707) 826-3427
mms818@humboldt.edu
Appendix A3: Interview Questions for Service Providers

I would like to thank you for meeting with me today. Over the past year I have questioned accessibility and awareness of autism services as they exist in Humboldt County. As a parent of a child with autism, I felt as though an examination of these services should be the basis of my Masters project. I have designed a two part needs assessment that will 1) conduct one-on-one confidential interviews with autism service provider employees to examine accessibility and barriers in regards to autism services offered in Humboldt County and 2) collect a self-administered paper based questionnaire of autism service provider employees, concentrating on need and awareness of autism services offered in Humboldt County. I will additionally, based on my analysis of the information collected, provide a needs assessment of the autism service provider organizations that I examine. I hope that my summary report will assist parents/caregivers and autism service providers in accessing and utilizing services available to individuals with autism spectrum disorder on a more transparent level.

Your participation is completely voluntary and you may withdraw from this interview at any time. Our conversation will be confidential. There will be no specific information on autism service provider organizations other than that they were assessed.

We will begin the process by engaging in a 30-45 minute one-on-one confidential interview. The second phase of the process involves your completion of a self-administered paper based questionnaire; this will take place as part of the interview. The questionnaire will take approximately 10-15 minutes to complete. As the questionnaire is self-administered, I am providing a self-sealing envelope for you to place it in upon completion.

I will now read to and with you your Informed Consent form. The confidential interview and self-administered questionnaire will take approximately 45-60 minutes. Do you feel as though you would like to proceed with the interview and questionnaire or would you like to withdraw from the study?

Autism is the fastest-growing serious developmental disability in the U.S. The Centers for Disease Control and Prevention propose that approximately one in eighty-eight American children are affected by autism spectrum disorder. As the prevalence of autism is increasing at staggering rates, I propose that a needs assessment of services available to individuals with a diagnosis of autism spectrum disorder is necessary for Humboldt County, CA. The focus of my study is to evaluate the ways in which access and barriers to services available in Humboldt County are impacting the utilization and awareness of autism services available.

1. What is your organization’s mission?
2. What is your organization’s formal vision or mission statement?
3. What are the goals of your organization?
4. What are the values of your organization?
5. Are any of these in writing? May I have a copy?
5a. How are these statements (vision/mission/goals/values) conveyed to staff?
6. What are the top 3-5 services that your clients access most frequently?
7. What are the top 3-5 services that your organization provides that your clients may experience barriers to accessing?
8. Here is a copy of an anonymous questionnaire that you will have 10-15 minutes to complete, seal in a self-sealing envelope and turn over to me.
9. Would you feel comfortable with me using small unidentified quotes from this interview in my final project?
10. Thank you for your participation in this study. Do you have any questions or final comments? My contact information is included on your Informed Consent letter and you can contact me at your leisure.

Martinek, Christina Ann Johansen. 2012. “Why Do Individuals Choose To Work For Nonprofit Social Service Organizations?” PHD dissertation, Department of Philosophy, Fielding Graduate University, Santa Barbara, CA.
Dear Parent:
I am a Sociology Masters Candidate at Humboldt State University examining access and barriers to services individuals with autism spectrum disorder may encounter in Humboldt County, CA. As the parent of a child with autism spectrum disorder, I feel it is important that local service providers are aware of the how important services are to parents/caregivers, their levels of awareness of these services, and whether they have experienced any difficulty receiving services.

Your involvement in the autism spectrum disorder community as a parent has made you eligible for participation in this study.

Participation will involve one-on-one interviews with parents/caregivers to examine accessibility, awareness and barriers in regards to autism services offered in Humboldt County. The process will involve a 30-45 minute one-on-one interview.

Your participation in this study will be voluntary and totally confidential. Thank you for your cooperation and consideration.

Sincerely,

Michelle Showers, Masters Student
Humboldt State University
mms818@humboldt.edu
(707) 826-3427
Appendix A5: Recruitment Letter 2

Awareness, Importance, and Access: Autism

Supports & Services

Parents/Caregivers of Individuals with Autism Spectrum Disorder

**What?**
Participate in 30-45 minute, confidential, one-on-one interviews

**Where?**
Eureka/Arcata/Mckinleyville/Fortuna Area

**Why?**
To examine access, importance and barriers to services individuals with autism spectrum disorder experience/have experienced in Humboldt County, CA
Appendix A6: Recruitment Letter 3

Dear Parent/Caregiver:
I am the parent of a child with autism who attends the Peninsula School in Manila. I am currently completing my Masters in Sociology at Humboldt State University. I need to speak to five more parent/caregivers about your experiences. I appreciate any time you have to speak with me.

Sincerely,
Michelle Showers
mms818@humboldt.edu
(707) 826-3427
Appendix A7: Interview Questions for Parents/Caregivers

I would like to thank you for meeting with me today. Over the past year I have questioned accessibility and awareness of autism services as they exist in Humboldt County. As a parent of a child with autism, I felt as though an examination of these services should be the basis of my Masters project. I have designed a two part needs assessment that will 1) conduct one-on-one confidential interviews with parents/caregivers to examine accessibility and barriers in regards to autism services offered in Humboldt County and 2) collect a self-administered paper based questionnaire of parents/caregivers, concentrating on need and awareness of autism services offered in Humboldt County. I will additionally, based on my analysis of the information collected, provide a needs assessment of the autism service provider organizations that I examine. I hope that my summary report will assist parents/caregivers and autism service providers in accessing and utilizing services available to individuals with autism spectrum disorder on a more transparent level.

Your participation is completely voluntary and you may withdraw from this interview at any time. Our conversation will be confidential. There will be no specific information on autism service provider organizations other than that they were assessed.

We will begin the process by engaging in a 30-45 minute one-on-one confidential interview. The second phase of the process involved your completion of a self-administered paper based questionnaire; this will take place as part of the interview. The questionnaire will approximately 10-15 minutes to complete. As the questionnaire is self-
administered, I am providing a self-sealing envelope for you to place it in upon completion.

I will now read to and with you your Informed Consent form. The confidential interview and self-administered questionnaire will take approximately 45-60 minutes. Do you feel as though you would like to proceed with the interview and questionnaire or would you like to withdraw from the study?

Autism is the fastest-growing serious developmental disability in the U.S. The Centers for Disease Control and Prevention propose that approximately 1 in 88 American children are affected by autism spectrum disorder. As the prevalence of autism is increasing at staggering rates, I propose that a needs assessment of services available to individuals with a diagnosis of autism spectrum disorder is necessary for Humboldt County, CA. The focus of my study is to evaluate the ways in which access and barriers to services available in Humboldt County are impacting the utilization and awareness of autism services available.

1. At what age was your child diagnosed with autism spectrum disorder?
2. Where does your child fall on the autism spectrum disorder scale?
3. Please describe the process that you engaged in to access services for your child.
4. What service providers do you utilize to access services for your child?
5. What services does your child currently receive?
6. In your opinion, do you think that the process of locating services was straightforward?
7. In your opinion, do you think that the process of accessing services was straightforward?

8. In your opinion, what barriers have you encountered to locating services?

9. In your opinion, what barriers have you encountered to accessing services once you located them?

10. Would you feel comfortable with me using small unidentified quotes from this interview in my final project?

11. Thank you for your participation in this study. Do you have any questions or final comments? My contact information is included on your Informed Consent letter and you can contact me at your leisure.