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Parents' Perceptions of Social Service Supports for Families Raising a Child with an Autism Spectrum Disorder

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**Parents' Perceptions of Social Service Supports for Families Raising a Child with an
Autism Spectrum Disorder**

Lisa Holmquist-Arndt

A Thesis

Submitted to the Graduate Faculty of

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Thesis Committee:
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Abstract

Autism Spectrum Disorder (ASD) is typically diagnosed in childhood and has a wide range of symptoms, some being more severe than others. The purpose of this research was to examine ASD and how it is impacting families in a community. Along with the perspective and family systems theory promote resiliency among families who are impacted by an ASD diagnosis.

In this study, qualitative research was used. Qualitative research includes data collection, data analysis, and drawing conclusions. This study is based off of interviews of parent perspective.

This research produced both strengths and limitations. The implications of this research allow current and future social workers to relate and work with families who have a child with an autism diagnosis and the community supports that are available for them.

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Chapter 1: Introduction

Parenting may be challenging, but when raising a child with autism, the parenting tasks maybe different and the challenges can be greater than what are experienced by parents who do not have a child with autism spectrum disorder.

Parents may wonder if they can better advocate for their child with autism along with accessing proper supports, especially via the county for services. This study seeks to identify whether or not county services for children with autism are helping with the support parents/guardians need.

Having a child with autism can be associated with additional parental/family stressors. Children with Autism Spectrum Disorder typically have significant challenges in communication and learning due to issues related to emotional expression and language impairments, and there is a need to continually be vigilant about and manage behaviors such as aggression and stereotypical movements. There may be extra care giving needs due to the child's lack of self-care skills and an ongoing dependency need to advocate on behalf of the child, particularly with schools and mental health and social agencies (Phetrasuwan & Shandor-Miles, 2009).

Also, Osborne, McHugh, Saunder, and Reed (2008) stated that “There are two lines of evidence that point to the importance of studying the relationship between parenting stress and the outcomes of early teaching interventions for children with ASD. Firstly, levels of stress experienced by the parents of children with ASD are enormously high, compared to those experienced by parents of children with almost any other type of disability or health problem and secondly, there are numerous interventions that recognize how family functioning may influence the behavior of a child with special needs. Given that parenting stress appears to be related to

child outcomes, and given that many early teaching interventions require long-term, intensive, and intrusive access to the family home and often recruit parents as therapists” (p. 1092).

Parenting a son or daughter with ASD may pose several unique challenges which may take a toll on a marriage. “The extent of this toll in terms of divorce has been a topic of a wide speculation in the media, with divorce rates of 80% and/or higher, but the issue has not yet been addressed by empirical research (Hartley, et al., 2010, p. 2). Despite high rates of marital conflict, many couples do not reach out for couple’s therapy. Lack of respite is a major reason. For most, finding a babysitter with whom they can safely leave an autistic child who has toileting concerns, few communication skills, aggression and other inappropriate behaviors on a regular basis is difficult. Another reason is parents’ lack of belief that they will find a therapist understanding of their particular circumstance (Hartley et al., 2010, p. 2).

Keeping any marriage healthy takes time and, all too often, time gets swallowed up by the autistic child’s needs. “Many children with Autism Spectrum Disorder have difficulty sleeping, meaning that at least one of the parents is sleep deprived. Usually, a role division takes place as one parent, usually mom, becomes the autism expert, while dad works harder to earn money or opts out” (Sicile-Kira, 2013).

Becoming an advocate for one's child can also be a role that many parents take on. “The role of advocate is familiar to many parents. Parents intercede on behalf of their children at school, at clubs or in the street and this advocacy role sometimes continues into young adulthood. However, for parents of disabled children, evidence suggests that the advocacy role

develops to a level of frequency and complexity, which other parents do not usually face” (Ryan & Cole, 2008, p. 43).

Research Question

What social services/supports have been offered by a county social service agency/professional and what services/supports did you choose to use to support your efforts to raise your child/ren with an Autism Spectrum Disorder (ASD)?

Significance to the Field

The author is interested in collecting data and comparing parents' perceptions in one western Minnesota county who are raising children with Autism Spectrum Disorders. Information about supports for family's perceptions of supports will be useful for a better understanding of what those agencies that work with parents can expect to see when they are working with a family that has a child with autism. Then these agencies can better assist them so they are making wise decisions about how to help their child. Also, these survey questions may be used as a guiding tool for providers of services for these families.

Definitions

To prevent any misunderstandings or any confusion, key terminology will be defined.

Autism Spectrum Disorder (ASD): A complex neurobiological disorder with symptoms that seriously affect the child's social interaction capabilities: has verbal and nonverbal communication and repertoire of activities and interests (Gal, et al., 2009).

Asperger's Disorder: The pervasive developmental disorders characterized by severe and sustained impairment in social interaction and the development of restricted, repetitive patterns of behaviors, interests, and activities causing impairment in most areas of functioning.

Similar to autistic disorder but with later onset, the individual with the disorder usually has difficulties in social interactions throughout life (Barker, 2003)

Applied Behavior Analysis (ABA): Offers the scientific basis for a range of well-known intervention strategies. (Dillenburger, Keenan, Doherty, Byrne, & Gallagher, 2010).

Personal Care Assistance (PCA): The Personal Care Assistant: program provides services to persons who need help with day-to-day activities to allow them be more independent in their own home. A personal care assistant is an individual trained to help persons with basic daily routines. A PCA may be able to help you if you have a physical, emotional or mental disability, a chronic illness or an injury (Minnesota Department of Human Services, 2011).

Social Welfare: “When a society strives for community betterment by developing methods and programs to promote social justice and address social needs” (Colby & Dziegielewski, 2004, p. 28).

Social Work: “The field of social work involves working actively to change the social, cultural, psychological and larger societal conditions that most individuals, families, groups and communities face” (Colby & Dziegielewski, 2004, p. 10).

Chapter 2: Literature Review

Causes of Autism

Autism Spectrum Disorder (ASD) is a cluster of life-long neurodevelopmental disorders composed of Autistic Disorder, and Asperger Syndrome. These disorders can be marked by significant qualitative limitations in: social interactions, verbal and nonverbal communication, and restricted repetitive and stereotyped patterns of behavior, interests, and activities (Kogan, et al., 2008).

Diagnostic Process

According to National Institute of Mental Health (NIMH: 2013), “ASD is diagnosed according to guidelines listed in the *Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition-Text Revision* (DSM-IV-TR). The manual currently defines five disorders, sometimes called Pervasive Developmental Disorders (PDDs), as ASD:

- Asperger's Disorder (Asperger syndrome)
- Pervasive Developmental Disorder not otherwise specified (PDD-NOS)
- Rett's Disorder (Rett syndrome)
- Childhood Disintegrative Disorder (CDD)

Symptoms of Autism Spectrum Disorder (ASD) vary from one child to the next, but in general, they fall into three areas:

- Social impairment
- Communication difficulties
- Repetitive and stereotyped behaviors

Children with ASD do not follow typical patterns when developing social and communication skills. Parents are usually the first to notice unusual behaviors in their child. Often, certain behaviors become more noticeable when comparing children of the same age.

No two children express exactly the same types and severity of symptoms. In fact, many typically developing children occasionally display some of the behaviors common to children with ASD” (NIMH, 2013).

Treatment

Early intervention is important since the brain is more easily influenced in early childhood. Intervention programs can help provide parents with effective ways of teaching their child and reducing the challenges of ASD. Disruptive behavior can be a major source of stress for those who care for a child with autism. Programs which teach parents how to manage challenging behavior have the potential to reduce parental stress and maternal depression (Birkin, Anderson, Seymour, & Moore, 2008).

In addition, Birkin et al. (2008) stated that there is no single treatment for autism; treatments generally address behavioral and learning skills. Treatments can include intensive skill-building and teaching educational sessions known as applied behavior analysis or ABA, and many recent, more interactive, child-centered versions of behavior treatments. Treatment may also involve special training and support for parents, speech and language therapy, occupational therapy, and/or social skills training.

Challenges of Children with Autism and their Families

There are many types of challenges that children and their families face. One challenge is funding for proper health care for children. According to Gabovitch and Curtin (2009), children with ASD are at risk for many types of chronic conditions and require services far beyond those of children in general. Private and public health care plans do not provide adequate coverage for the types of services these children and families need. Having specialty care can be problematic because health care plans often do not cover subspecialists or subspecialty services, and referrals can be difficult to achieve.

Health care plans often require multiple levels of approvals and can be difficult to coordinate. Many families may pay out of pocket for mental health services and even more report problems finding skilled and experienced mental health clinicians and in coordinating services between the child's mental health provider and other clinicians (Gabovitch & Curtin, 2009).

Another major significant obstacle that most families face is trying to coordinate the health care and the education systems. A cooperative and communicative partnership between these systems working with the family is critical for determining and delivering appropriate services, minimizing misunderstandings and promoting quality of care. However, medical and educational systems' delivery of care can often be inconsistent (Gabovitch & Curtin, 2009).

Coping Strategies

Based on clinical experience, the general literature on family coping, and some preliminary results from ongoing research, one can speculate on the differences between crises

prone or high risk families and families which are somehow coping successfully with their child with Autism (Bristol & Schopler, 1984).

Also, Gabovitch and Curtin (2009) stated that an individual's capacity for resilience, the style of coping, sense of self-efficacy, and response to family dynamics are all factors that contribute to how one responds to having a child with autism. These authors further stated that the level of the child's behaviors may significantly affect a mother's own stress and may cause depression. Mothers are also particularly prone to more physical illness as a result of their child's disability.

According to the American Psychiatric Association (2012), "Having a child with autism affects the whole family. It can be stressful, time-consuming, and expensive. Paying attention to the physical and emotional health of the whole family is important. Many national and local advocacy organizations provide information, resources and support individuals with Autism Spectrum Disorders and their families."

Parenting a child with a disability such as autism is particularly stressful, more stressful than parenting a child who is developing typically (Hoffman, Sweeney, Hodge, Lopez-Wagner, & Looney, 2009). Also, studies have shown a relationship between the severity of the behavioral problems of the child and the level of parental stress. Different families use varying coping mechanisms depending on family beliefs and family structure, among other things. Gray (2006) stated: "As a challenge to the family, autism must rank among the most stressful of childhood developmental disabilities. Along with problems with communication, emotional expression and antisocial behaviors, all combine to place tremendous stress on the families of children with autism" (p. 970).

Another factor that contributes to how a family copes with autism is the beliefs of the parents. According to Bristol and Schopler (1984), parental beliefs are important to family coping. Family crisis is less likely to occur in cases where the family believes the stressful event is due not to their own inadequacy, but to circumstances outside the family, and the belief that others are also involved in these circumstances. The authors stated that informal social support for the family is a positive. Having a good support system is something important to most families of children with autism. This may include immediate and extended family, friends, close neighbors, and support groups that families may be a part of (Bristol & Schopler, 1984).

Importance of Support

Receiving support from family, friends, and outside resources can provide a less stressful and overwhelmed feeling for parents. Key supports for family members who are raising a child with ASD are: Personal Care Assistant hours, having the school provide support for their children, having the community be involved with understanding what autism is and having the proper resources given to the parents. Having these supports from family, friends, and outside resources can be a key for helpful guidance and also positive supports (Koegel, Symon, & Koegel, 2002). According to Koegel et al., children being diagnosed with autism spectrum disorders is dramatically rising. With this being said, having any additional services are necessary to meet the needs of these children and their families.

General support such as PCA services for families provided by social, education or health services has a positive impact on parental stress. According to Dillenburger et al. (2010), “limited financial resources, lack of appropriate services and insufficient support are generally held to contribute to poor prognosis. Social support on its own is not enough. The expertise of

those providing support is an important factor in the alleviation of parental stress, in particular in relation to self-efficacy, behavior management and provision of home based care.”

Social Service and Supports

When looking for proper supports from social services, the intensity and quality of services is often difficult to provide with budgetary constraints and problems retaining staff with the sufficient training that is needed. Public programs have been faced with criticism and legal action from families concerned that their children were not receiving appropriate services (Stahmer, 2007).

Trying to find support can be challenging when funding is not always there. According to Dillenburger et al. (2010):

General support for families provided by social, education or health services has a positive impact on parental stress, while limited financial resources, lack of appropriate services and insufficient supports are generally held to contribute to poor prognosis. Concerns about adequate financial resources in relation to school, therapy and medical services can also add stress. Social support on its own is not enough. The expertise of those providing support is an important factor in the alleviation of parental stress, in particular in relation to self-efficacy, behavior management and provision of home-based care. (p. 14)

Living in a rural area and having a child with autism can also have a negative impact on services that may be provided for the individual and/or family:

Rural dwellers experience disadvantages compared to those who live in urban environments. The key challenges to obtaining resources and services in remote areas are transportation, lack of local support, isolation, few employment opportunities, geography, and limited financial resources. These challenges are compounded when an individual who lives in a rural area also has a disability...two key variables that affect service delivery to remote locations are population density and topography. (Symon, 2001, p. 162).

Also, Murphy and Ruble (2008) stated that:

compared to children living in metropolitan areas, children residing in rural areas have access to few mental health and child pediatric services. Children from rural areas

received a diagnosis at a later age than children from urban areas. Confirmed this finding and specified that children with ASD in rural areas engaged in longer diagnostic process compared to their urban counterparts. Because the critical first step following the diagnosis is receipt of specialized intervention services, these findings suggest a need for more research about the diagnostic experiences regarding services used by children with autism in rural areas and subsequent effects on accessibility to specialist services. (p. 3)

Social services can provide many positive outcomes too, especially when someone is working with an experienced social worker. Social services can provide much needed services for families or caregivers with autistic children. Examples of social services which may provide help if parents qualify are: home-based respite care, family based short-term respite care, after school activities for children, and residential schools (Glen, 2008).

Social Services Programs

Many professionals provide services for children with disabilities and their families.

According to Dempsey, Keen, Pennell, O'Reilly and Neilands (2009):

family systems theories underpin many models of service delivery that recognize the interrelatedness of family members and the importance of acknowledging the needs of all family members, not just those of a family member with a disability. They further assert four crucial beliefs that drive the implementation of family-centered services. First, the family and not the professional is the constant in the child's life. Second, the family is in the best position to determine the needs and well-being of the child. Third, the child is best helped by also helping the family, and this help may extend to an understanding of the family's community and to providing information that the family needs. Finally, respecting family choice and decision making in the provision of services, showing respect and affirming families' strengths, enhancing family control over the services they receive, and partnerships and collaborations with families are emphasized. (p. 4)

Social workers are people who provide a range and level of services that are appropriate to promote the welfare of children in need. According to O'Halloran (2000), any child who may be in need and is assessed by social services may qualify for accommodations. The aim is to ensure that families with a child in need can look to social services for advice and support if they need help in coping. O'Halloran further stated social services may recover the cost of providing

services, except for advice, guidance or counseling, if the social worker believes that the child or family can reasonably afford it and the family or child is not getting income support, family credit, disability, working allowance or an income-based allowance. By providing services to children and families in need, social services should be able to prevent serious issues that may arise.

Public Social Service Supports for Children with ASD

According to Blackwell (2011):

the national economic downturn persists; causing public revenues to decrease, states are challenged to meet the growing demand for publicly financed services to individuals diagnosed with ASD. To make the most effective use of limited resources, federal and state policymakers need empirical data to make informed decisions about which services and support systems are safe and cost-effective in meeting the complex needs of children, adolescents, and adults with ASD. Few initiatives have focused on providing information about the most effective services for individuals with ASD. Those that do, such as the National Standards Project (NSP), have primarily addressed the needs of individuals under age 21 years. Although these efforts provide critical information about effective services and supports for individuals with ASD, gaps exist in information about promising services for transition-age youth and adults. In particular, prior to this study, no efforts at the national level examined ASD services and supports within the context of Medicaid which is the main public funder of such services outside the education system for affected individuals and their families. (p. 1)

The Help with Services for Children with Autism Spectrum Disorders (2013) brochure noted:

In Minnesota, there is no separate, specific program for children with ASD. Some children with ASD may have mental health needs. A mental health professional can do a diagnostic assessment to determine if your child has a mental health diagnosis that would benefit from a mental health treatment plan and services.

Mental health services include psychotherapy (individual, family, or group) and skills training, which can help your child practice skills missed because of a mental health condition. The Minnesota Department of Human Services offers many programs, including those for health care, people with physical and developmental disabilities, and children's mental health services. (sec. 1)

The MN DHS has an entire webpage dedicated to assisting families that are raising children with ASD.

There are many county supports in Minnesota with resources that can be provided for families who parent children with ASD. Help Me Grow is a resource program in Dakota County for which children with developmental delays may be eligible along with ASD. Anoka County also offers an Autism Resource Guide. This guide is very helpful with explaining what autism is and what steps are needed to help or better oneself. A lot of resources are mentioned and contact names are also included. Washington County also offers a Resource Guide much like Anoka County. The booklet includes many good resources along with supports of parents/guardians as well as references that are provided in the area. There are full time social workers who are able to help if needed. Carver County has a link to connect to the Minnesota Department of Education-Autism Information.

According to the Wright County (2010) web page:

Families of children on the autism spectrum often struggle in finding appropriate care for their child as well as the funding needed to pay for the care and the items needed to ensure health and safety (fences, door alarms, therapy equipment, and communication tools). Many of the therapies/services for individuals on the Autism Spectrum are covered by private insurance or Medical Assistance (i.e. Speech, OT, PT, ABA, and Personal Care Attendant (PCA)). For services/items not covered by insurance, other options include; Grants (Family Support Grant, Consumer Support Grant) and Waivers (DD Waiver, CADI Waiver). Grants and Waivers are only available to individuals who receive Medical Assistance and have an open Social Services case.

Wright County (2010) stated vocational options for adults can range from competitive employment with minimal support to in center day programs with significant staffing support. Funding for vocational programs can come from Vocational Rehabilitation programs, waivers or county funding. Living situations can vary as well depending on a person's skills and

independence. Some individuals live independently with minor adaptations or supports and some need 24 hour supervision with highly trained staff. Families and individuals should be in contact with their local social service agency at least 2 or 3 years prior to finishing school if they do not already have an open case.

Services/Funding

Many families would like the help or have received help from the county from funding to even therapy. Wright County (2010) stated, “Many of the therapies/services for individuals on the Autism Spectrum are covered by private insurance or Medical Assistance (i.e., Speech, OT, PT, ABA, and Personal Care Attendant [PCA]). For services/items not covered by insurance, other options include; Grants (Family Support Grant, Consumer Support Grant) and Waivers (DD Waiver, CADI Waiver). Grants and Waivers are only available to individuals who receive Medical Assistance and have an open Social Services case. Vocational options for adults can range from competitive employment with minimal support to in center day programs with significant staffing support. Funding for vocational programs can come from Vocational Rehabilitation programs, waivers or county funding. Living situations can vary as well depending on a person’s skills and independence.

Some individuals live independently with minor adaptations or supports and some need 24 hour supervision with highly trained staff. Families and individuals should be in contact with their local social service agency at least 2 or 3 years prior to finishing school if they do not already have an open case. It is vitally important to have this time to discuss and plan for the transition into adult life from school. Providing appropriate services and supports for individuals affected by Autism does not come cheap. According to a 2006 Harvard study, caring for an

individual with Autism can cost an estimated \$3.2 million in their lifetime. Caring for all people with Autism over their lifetimes costs an estimated \$35 billion per year.

Parents' Perceptions of County Social Service Programs and Supports

Wright County's Autism Allies Group (2010) noted that Minnesota conducted a survey serving the Wright County area. This survey became a learning tool to help better the county services and their providers to learn more about autism. The survey included: schools, service providers, health care providers, child care providers, training, and community.

The survey tool was similar to this researcher's tool that was used in conducting his study. This researcher wanted to see what parents' perceptions of social services were and whether or not these services were being obtained by the members of the support groups.

According to Wright County's Autism Allies Group (2010), parents would have liked to see more respite services, along with in home services, and more experienced ASD-specific therapy providers in the Wright County area (ABA). Parents also expressed a need:

- clearly explain guidelines for eligibility"
- promptly respond to phone calls
- provide more staff
- access in navigating the county system,
- assume that parents will not be judged if they ask, provide direction and resources and explain/estimate Medical Assistance and TEFRA fees early in the process of applying for services (p. 39)

Cultural Considerations

The Autism Society of Minnesota (2011) gives supportive material on autism and how people of color may find the help that may be needed. Provided resources are in: Spanish, Somali, Hmong, and English. According to the Minnesota Governor's Autism Spectrum

Disorder Task Force (2012), “The task force recommends the development of a Minnesota Guidebook for ASD. It states that:

navigating through the system to find the appropriate services and treatments for individuals with ASD can be daunting. Several states have developed guide books, the task force recommends using the guide book from the state of Washington as a model. Both printed and electronic copies should be made available to individuals, families and professionals. Ideally it should be reviewed and updated if necessary every three years. This guidebook should be made available in Spanish, Hmong, Somali, and other languages upon request (p. 3)

The Minnesota Department of Human Services also provides brochures about autism in English, Hmong, Somali, Spanish, and also Vietnamese. Also, the Minnesota Department of Human Services (2011) noted that:

in Minnesota, there is no separate, specific program for persons with ASD. Many of the available services are provided through county, tribal, and state programs that serve people with disabilities, including children with ASD. County public health or social services or tribal agencies can provide local information and referrals, including advocacy, child care, community resources, county services, education, and medical specialists. Children with ASD often need supports and services to learn and develop certain skills. Depending on their symptoms and severity, they may benefit from different types of services delivered in different types of places. (p. 2)

Relevant Theory

The relevant theory guiding this research is Family Systems Theory. Murray Bowen is the theorist. This is an appropriate model to assist in helping understand the impacts Autism can have among family members who are presently in the family unit. Family Systems Theory is defined as members of the family intertwining together and working as a unit to help oneself or each other.

Family systems theory can also help us understand how a family system is intertwined. According to Zastrow and Kirst-Ashman (2007):

Each member of a family is affected by what happens to any of the other members. Each member and the family as a whole are also affected by the many other systems in the family's environment. Also, families are composed of the number of individuals, the elements that make up the system. Each individual has a unique relationship with the other individuals in the family. Regardless of what the relationship is, together the family members function as a whole family system. (pp. 137-138)

“Family stress associated with limited financial resources, lack of appropriate services and limited financial resources, and insufficient support systems are examples of family system risk factors that can contribute to unfavorable prognoses” (Symon, 2001, p. 160).

According to Allen (2007), “Family systems theory is more than a therapeutic technique. It is a philosophy that searches for the causes of behavior, not in the individual alone, but in the interactions among the members of a group. Allen also stated that the family systems approach is based on several basic assumptions:

- Each family is unique, due to the infinite variations in personal characteristics and cultural and ideological styles;
- The family is an interactional system whose component parts have constantly shifting boundaries and varying degrees of resistance to change;
- Families must fulfill a variety of functions for each member, both collectively and individually, if each member is to grow and develop; and
- Families pass through developmental and non-developmental changes that produce varying amounts of stress affecting all members

Summary

This review of literature points out: the cause of Autism, diagnostic process, treatment, challenges, coping strategies, importance of support, social service and supporting social services programs, parents' perceptions, and cultural considerations. Having a better understanding of

the challenges of autism will help with identifying the means to find the supports needed for family and children with autism. The review of literature can also be used as a knowledge base for caregivers and professionals, as well as providing this researcher with information needed to develop and conduct this study.

Chapter 3: Methodology

The Design of the Study

This study seeks to explore parents' raising children with Autism Spectrum Disorders (ASD) perceptions of county social services. The research question is: What social services/supports have been offered by a county social service agency/professional and what services/supports did you choose to use to support your efforts to raise your child/ren with an Autism Spectrum Disorder (ASD)? My hypothesis is that parents do have perceptions of local county social services and that their noted perceptions will be similar to data provided in the author's review of the literature and previous professional experience working in a county social service agency with parents who were raising child/ren with ASD. If this hypothesis is true, then it would further validate, although with somewhat limited validity given a small sample being surveyed, that social service agencies and professionals can assume there are some general consistent perceptions parents have about social services.

The benefits of knowing this data can be that parents can work together across the nation to develop these perceptions into uniform platforms that may be used to inform legislators, create policy and most importantly this data can be used by social services agencies to help social service agencies and professionals to create parent informed evidence based programming that parents perceive as helpful to their families.

The Research Design

This research design is a quantitative descriptive study that will utilize a non probability purposive sampling technique with volunteer participants' data being collected via a basic survey tool which is similar to various tools utilized in the comparison studies. The independent

variable is whether or not the parent has perceptions about social services and the dependent variable is whether or not they are consistent with existing data sets. The survey tool consists of a basic demographic section and a parent perception questionnaire. This tool has been reviewed and approved for use by a team of disability professionals that also are parents of children with disabilities, as well as approved by the host agency, The host agency staff where the survey will be administered.

Potential Participants

Potential study participants (parents who are raising children with an Autism Spectrum Disorder) will be identified through the host agency ASD Parent Support Group facilitator (see agency agreement letter: Appendix A, B, C). The Resource Center purpose is to provide education, support, connections for family members and professionals of children, teens, or adults with disabilities. They also partner with local, regional, and state health and human service organizations, and educational, medical, service and nonprofit agencies and offers these two support groups in rural Minnesota. The parent support group is led by professional facilitators, and the groups are comprised of 60 parents who are raising children with ASD (and also open to parents of children with ADHD). The potential study participants (subjects) are the parents that attend this group and who self-identify that they are raising a child who has an autism spectrum disorder and that they attend this parent support group. The facilitators of the two groups have stated that many of the groups' participants have/or currently use county social services and supports.

Data Collection Methods

The researcher supplied the facilitators with the study materials (informed consent and parent survey) representative of the possible study participant sample size. The facilitators read the informed consent information to these identified possible study participants and invited group members to participate if they so chose to by completing the survey as indicated within the study materials.

The facilitators of these groups and the agency agreed to provide a portion of one of each of the group's sessions in January, 2013, to be used to conduct this study. Those members of the group that wished to be a part of the study were given group session time to further individually review the study materials and complete the survey tool if they wished to.

Once these study participants completed the survey they placed the tool in the researcher provided envelope, sealed it, and returned it to the facilitators. The researcher met with the facilitators after the group sessions ended to collect the completed surveys. The collected surveys, which were reviewed by only the researcher, were maintained in a locked file cabinet when not being reviewed via email.

Given the voluntary nature of this study and the procedural safeguards provided to participants vs. identifying data collected such as names, researcher precautions for maintaining confidentiality of participants, and ability for participants to select and answer only the questions they felt comfortable answering) there was limited, if any, risk of harm to participants choosing to participate in this study.

Data Analysis

The data analysis plan is to collect the responses collected from individual voluntary participants were coded by the researcher in relation to general themes/topics and cross analyzed with existing data sets also grouped by these themes/topics in an attempt to compare participants' responses to existing data sets and address the research question.

Summary

When taking a look at the design of study, research design, potential participants, data collection, and data analysis. The seeking parents that have a child with Autism with the participation of local county social services may add a helpful of support and guidance and a better understanding of what to do when the help is needed. Also, the quantitative data utilized a non-probability purposive sampling technique when sampling parents for a result. The participants were identified through The Resource Center's ASD parent support group meeting. With the understanding that and agreement that the group members would have a confidential survey with no names given out. Also, parents did not have to answer a question if they felt uncomfortable.

Chapter 4: Findings

The purpose of this study was to explore parents' raising children with Autism Spectrum Disorders (ASD) perceptions of county social services. The benefit of knowing this data can be that parents can work together across the nation to develop these perceptions into uniform platforms which may be used to inform legislators, create policy development, and most importantly help social service agencies and professionals create parent informed evidence-based family programming that parents perceive as helpful to their families.

The host agency ASD Parent Support Group Facilitators collected six total surveys between the two groups from participants. They stated that approximately 60 parents are enrolled as potential members of the two groups and on average 30 attend the monthly support group sessions.

Research Question

What social services/supports have been offered by a county social service agency/professional and what services/supports did you choose to use to support your efforts to raise your child/ren with an Autism Spectrum Disorder (ASD)?

Description of the Sample

The researcher was able to get six responses and the other group that also has an autism support group had no respondents. The sample size consisted of two rural counties that have 30 members who may attend meetings. The sample size was a total of six individuals who were active in taking the survey. The characteristics of this sample were all white women who were 25-40 years old. All women were married and had children who were school aged. All children had been diagnosed with Autism and/or Asperger's Disorder.

Demographic Information

All children lived at home with both parents as their guardians. These children who were surveyed by their moms indicated that all children were Caucasian. As indicated from the surveys, all children are receiving services from the school and also the county setting.

The responses collected from individual voluntary participants were coded by the researcher in relation to general themes, topics, service providers, the county, community, and schools. Similar information was collected in an earlier study done by Wright County Social Services (2010). The data from this Wright County study was cross analyzed with existing data. The current study data was also grouped by themes in an attempt to compare participants' responses to existing data sets from Wright County and address the research question.

Findings for Questions Used in Survey

What social services/supports have been offered by a county social service agency/professional and what services/supports did you choose to use?

All six parents/guardians commented “offered, but didn’t need.” One of the six responded with “Gillette Children’s” (hospital) and the other responded “Community Alternatives for Disabled Individuals (CADI) but didn’t want to use due to age of their child.” Also, one these two parents indicated that “my county social worker said I lived in a rural area and there are not a lot of services- so we are trying to decide what/where to go for resources for you.”

All six parents/guardians also responded that they had not been offered county social services that could have been helpful for them as parents. All six parents stated that many services usually are helpful, sometimes redundant. Another response from one participant was,

“Support groups, being connected with other individuals that are going through the same issues and also Personal Care Assist (PCA)/Respite seem to help when needing a break.” Another parent indicated that “A list of services, or providers that someone wants--No real help from the social worker. It has been very frustrating as rural areas don’t offer much.”

Parent Survey Results

Table 1: Participant Demographics

| Parent Responses (N=6) | Q. 1 Parent of Child with ASD | Q. 2 Parenting how Many Children with ASD | Q. 3 Diagnosed with ASD | Q. 4 Used County Social Services | Q. 5 Other Services or Supports Used |
|---------------------------|-------------------------------------|--|-------------------------------|--|---|
| Yes | 6 | 6 | 6 | 6 | 6 |
| No | 0 | 0 | 0 | 0 | 0 |
| Total Number | 6 | 1 child/per family | | | |

The researcher was able to get six responses and the other group that also has an autism support group had no respondents. The sample size consisted of two rural counties each with 30 members who may attend meetings. The sample size was a total of six individuals out of a possible 60 members who were sent the survey. Thus 10% responded the survey. The demographic characteristics of this sample were all white women who were 25-40 years old. Who all used county social services and supports to support their efforts to raise their child with ASD in a rural county?

Additional Demographic Findings from Comments on the Survey Findings from the Survey

All children lived at home with two parent families living in the same household vs. co-parenting children in two homes. These parents who were surveyed indicated that all the children with Autism were Caucasian. As indicated from the surveys, all children were receiving services from the school and also the county setting.

Findings from the Comparative Analysis of Parenting Survey

The responses collected from individual voluntary participants were coded by the researcher in relation to general themes, needs, topics related to autism, service providers, the county where they live, community, and schools. Similar information was collected in an earlier study done by Wright County Social Services (2010). The data from this Wright County study were cross-analyzed with existing data. The current study data were also grouped by themes in an attempt to compare participants' responses to existing data sets from Wright County and address the research question.

1. Study participants that are a parent of a child/ren with an Autism Spectrum Disorder (ASD)?
2. Number of children Participants are parenting that have an Autism Spectrum Disorder (ASD) and age ranges(s)?
3. Number of participants that have child/children that have been formally diagnosed with ASD (could note by data specifics below if you wish to) by a mental health/medical professional.

| Diagnosis | Age Diagnosed |
|-----------|---------------|
|-----------|---------------|

- Autistic disorder (also called “classic” autism)
- Asperger Syndrome
- Pervasive Developmental Disorder Not Otherwise Specified (or atypical autism)
- Childhood Disintegrative Disorder
- Rett Syndrome
- Other (please specify): _____

4. Number of participants that used county social services and/or supports to assist their family in raising your child/ren with an Autism Spectrum Disorder?

5. Number of participants that use other formal/informal services and supports to assist their family in raising your child/ren with an Autism Spectrum Disorder (such as special education school services, community supports, family, and friends?)

What formal or informal services and supports they used?

What of these services and supports they used did they find beneficial to their family?

Parent Survey

1. What social services/supports were offered by a county social service agency/professional to participants?

What services/supports of those offered did participants choose to use to support their efforts to raise their child/ren with an Autism Spectrum Disorder (ASD)?

- A. Offered to participants but participants chose not to use service/support and why
 - B. Offered and used and what participants found helpful/not helpful):
2. Are there other county social service supports and/or services that participants wished they were offered or that were available?

What did participants perceive these services would ideally provide and what did they perceive the benefit of these services/supports to be for the participant's child/ren and/or family?

3. What suggestions did participants have for improving or enhancing county social services being provided to families raising children with Autism Spectrum Disorders (ASD)?
4. Additional data shared by Participants in regards to parenting or raising a child with an Autism Spectrum Disorder (ASD)?

Do you have any suggestions to improve or enhance county social services being provided to families raising children with Autism Spectrum Disorders (ASD)?

All six parents who reported said PCA services have been very helpful and gave parents the opportunity to work full time and also have a break when needed. Family support groups have been another helpful tool which parents have used. (All the parents who took this survey have attended a monthly support group for parents of children with autism). As one parent stated this group provides "networking with each other and bouncing ideas from parent to parent has really helped us." The next closed-ended questions shown below had two parts that were explored: A) the desired supports and B) services parents would like to be offered by county services.

Desired Supports or Services

Three parents participating in the survey made comments on the first two questions:

3. What other county social service supports and/or services do you wish were offered or available and what would these services ideally provide and how would they benefit your child/ren and/or family?

One of the six parents indicated that “better training so parents can be better teachers and teachers can be more effective.” Some of the parents also stated that “more sensory therapy closer to home and also support groups closer to home. Also, parents/guardians would like to see Applied Behavioral Analysis (ABA) therapy available closer to home and a current list of resources available to family and family members.” In addition, six parents mentioned having more Personal Care Attendant (PCA) hours given to the family. As one parent wrote, “We could work more full time and have flexible hours when given PCA hours.”

Table 2: Question 1A: Social Services/Supports Offered/ Used by the County Social Services

| | A. Offered—Did Not Use | B. Offered and Used |
|------------------------------|------------------------|---------------------|
| Number of Parents Responding | 3 | 3 |
| Total: 6 | | |

1. What social services/supports have been offered by a county social service agency/professional and what services/supports did you choose to use?

As you can see in Table 2, three of six parents/guardians commented “offered, but didn’t need some county services.” One of the six responded with “Gillette Children’s” (hospital) and the other responded “Community Alternatives for Disabled Individuals (CADI), but didn’t want

to use due to age of their child.” Also, one these two parents indicated that “my county social worker said I lived in a rural area and there are not a lot of services—so we are trying to decide what/where to go for resources for you.” It would appear that they refused because they were not appropriate to their child with autism. All six participants were offered services, or the three that used services they used PCA services, in home therapy and school services. The outcomes were much maintained with the help and services that were given. The three participants that did not use services were due to time and driving to locations.

Table 3 shows all six parents stated that many services usually are helpful, sometimes redundant. Another response from one participant was: “Support groups, being connected with other individuals that are going through the same issues and also Personal Care Assist (PCA)/Respite seem to help when needing a break.” Another parent indicated that “A list of services, or providers that someone wants--No real help from the social worker. It has been very frustrating as rural areas don’t offer much.”

More Awareness

The second most important support that the group identified by parents was more awareness of what type of services were offered in a rural area. Many parents needed supports and felt they were not being provided with the types of support they needed. It was very important to parents to have services provided for them and to use them when needed. As one parent stated, “More people need to understand that it is a very difficult when raising a child with autism and having proper supports would help out a lot. Also, having more training for teachers, social workers and providers would help with meeting the needs of my child.” Another parent stated: “Being more aware of Autism will help with understanding the needs of my child.” This

could be just using proper terms when talking about how to handle a situation that could occur.

“We hope that the community in a rural town will come together and understand our kids are not monsters.”

Terry-Piper (2012) stated the impact of social stigma and social rejection were also noted with most parents stating that the negative impact of judgments of others may have decreased over time. Possible reasons for this include improved behavior in public as their children aged, and reduction of public outings in which the children participated in. Also, mothers reported that they learned to be tougher over time and became more comfortable speaking up about their child’s autism when others criticized or made negative remarks in any public settings.

Table 3: Question 2B: Wished Social Services/Supports Offered/Used by the County Social Services

| | Offered—Did Not Use | Offered and Used |
|------------------------------|---------------------|------------------|
| Number of Parents Responding | 3 | 3 |
| Total: 6 | | |

2. Are there other county social service supports and/or services that participants wished they were offered or that were available?

All six parents who reported said PCA services have been very helpful and gave parents the opportunity to work full time and also have a break when needed. Family support groups along with county support and services have been another helpful tool which parents have used. (All the parents who took this survey have attended a monthly support group for parents of children with Autism.) As one parent stated this group provides “networking with each other

and bouncing ideas from parent to parent has really helped us.” The next open-ended questions shown below had two parts that were explored: a) the desired supports, and b) services parents would like to be offered by county services.

Parents were asked if they could identify any desired supports or services that were needed. All six sets of parents gave suggestions to improve the services in this rural western Minnesota area. The following five themes were most important to these parents:

- Better training of social workers, teachers, and caregivers
- Sensory therapy closer to home
- ABA Therapy available and closer to home
- Current list of resources available to family
- PCA hours being more flexible

Table 4: Question 3C: Services You Wish were Offered or Available through County Social Services

| | A. Other Services—Wish were Offered | B. Other Services—Wish Were Available |
|------------------------------|-------------------------------------|---------------------------------------|
| Number of Parents Responding | 5 | 1 |
| Total: 6 | | |

3. What other county social service supports and/or services do you wish were offered or available? What would these services ideally provide and how would they benefit your child/ren and/or family?

One of the six parents indicated that “better training so parents can be better teachers and teachers can be more effective.” Some of the parents also stated that “more sensory therapy

closer to home and also support groups closer to home. Also, parents/guardians would like to see Applied Behavioral Analysis (ABA) therapy available closer to home and a current list of resources available to family and family members.” In addition, six parents mentioned having more Personal Care Attendant (PCA) hours given to the family. As one parent wrote, “We could work more full time and have flexible hours when given PCA hours.”

Table 5: Question 4D: Parent Suggestions to Improve or Enhance County Social Services

| | Improve Services | Enhance Services |
|--------------------------------------|------------------|------------------|
| Number of Parents Responding NONE | N/A | N/A |

No responses were noted in this section by participants.

Table 6: Question 5E: Other Parent Comments

| | On Parenting Child with ASD | On Raising Child with ASD |
|--------------------------------------|-----------------------------|---------------------------|
| Number of Parents Responding NONE | N/A | N/A |

No additional comments were made in this section.

Summary

When looking at the survey results, many of the participants have been or are working together with supports for their children that have Autism. Many parents use PCA services, county supports along with the school setting and family and friends for extra help. More

awareness is or can be needed for the general population in better serving their families they work with along with their child who has Autism. The survey questions show that needs may be met, but more knowledge is needed for a lasting outcome.

Chapter V: Discussion

The purpose of this study was to explore parent' raising children with Autism Spectrum Disorders (ASD) perceptions of county social services. The benefits of collecting this data can be that parents can work together across the nation to develop these perceptions into uniform platforms that can be used to inform legislators, contribute to policy development and most importantly help social service agencies and professionals to create parent informed evidence-based programming that parents percieve as helpful to their families.

The qualitative section was valid for the six individuals who took part in the survey that was given. The survey was analyzed to determine the most relevant statements, and the most needed services that parents/guardians felt would help them. The most frequently mentioned response by those parents completing the survey was to access and utilize community supports.

Using family systems theory as a key tool when working with families who may have an autistic child will help with a better understanding. Dempsey et al. (2009) stated that“ family systems theories underpin many models of service delivery that recognize the interrelatedness of family members and the importance of acknowledging the needs of all family members, not just those of a family member with a disability” (p. 4).

The research question was formed to assess parents' perception of proper supports. Given that the parents surveyed lived in a rural county and that because they were members of a support group, it was felt that they would have greater awareness of the supports that were needed for parents. This study was designed to support: (a) Identify supports in a small Midwestern rural area of Minnesota and any resources available; (b) identifying any resources

for parents that live in the community. Overall, this study identified many gaps in the services provided for parents who are/have been impacted by ASD.

Of those who chose to respond to the questions from the qualitative portion, the answers were compiled and analyzed for any common themes. The themes for each question will be examined more closely in the next section.

Desired Supports or Services and Suggestions

The next question asked was: If parents could identify any desired supports or services that were needed. All six sets of parents gave suggestions to improve the services in this rural western Minnesota area. The following five themes were most important to these parents:

- Better training of social workers, teachers, and caregivers
- Sensory therapy closer to home
- ABA Therapy available and closer to home
- Current list of resources available to family
- PCA hours being more flexible

Discussion of Findings

In the literature review it mentioned having proper supports in the home setting and having social services available. Limited research has been conducted on supports for families, and especially parents with children with autism living in a rural area. This study developed a measurement tool which can be reused in the near future to continue to assess progress in providing services to parents and to be helpful when serving parents.

This can also be very helpful for parents who may be interested in finding more information and how to be advocates for themselves. This tool will give them a better idea of what to look for and how to ask the questions they may need. With a focus on the many positive outcomes parents have shown from this study, it should be very helpful to future parents raising children with ASD as well as providers of service to them.

Limitations

At the planned time for the survey to be administered to parents in the support group the winter weather conditions prevented parents from attending this session. As a result, the researcher requested that the IRB committee allow this researcher to send out the survey to the parents support members via email. This IRB was approved.

Given the nature of the research study, the following limitations were considered. Whether or not this survey is deemed effective for parents receiving the services for their children, this research will not be able to determine the most effective components in what is being done. It would be possible that certain questions on this survey might be more effective than others in ensuring that appropriate needs are being met by the school and county for families that include a child with autism.

Another limitation would be having the individual take the survey on their free time rather than in a group setting as originally planned. This independent survey participation may create a situation where the survey may get set aside, and would more likely be lost or thrown

Policy and Practice

This section summarizes the policy and practice recommendations that were identified throughout the survey and how each answer emerged from results from this study. The intent of

this study was not to criticize others or critique services that have been in place, but instead to make others more aware of what service needs might not have been met for families or parents that need to be addressed or brought to attention in the Minnesota communities involved. This study has shown more needs still to be met along with providing current services with advocates, the school system, and also the community and professionals working in the field of social work to better serve parents of children with ASD.

The Autism Spectrum Disorder Task Force (2012) stated:

Autism Spectrum Disorder is the fastest growing developmental disorder in the United States. It affects one in every 110 children and it is four times more likely in males than females. Since 1993 there has been an increase of more than 160% in the prevalence of ASD between the ages of 6 and 22 years in Minnesota. Minnesota's December 1, 2010, Child Count data indicates that there are presently 14, 646 students identified with ASD as their primary disability in Minnesota schools from birth to 21 years and who are receiving special education and related services in our schools. (p. 2)

Gabovitch and Curtin (2009) stated that major significant obstacles for most families is to try to coordinate the health care and education systems. Parents who were surveyed stated that there was a need for better training for providers.

This was something that needed to be examined along with more community services for families and parents in more rural areas. Also, parents wanted to see all professionals involved with autism including social workers take part in becoming aware of current services along with using correct wording when talking to family members about their children/child. Programs with support groups do meet in the area where the survey was conducted. However, parents would like to see more support group meetings along with the ability to travel a shorter distance to the meeting.

Also, parents indicated they would like to see more PCA hours for their children. This would give parents more time to work or have time to go buy groceries. In addition, having PCA services with more flexible hours would provide more support to parents with their children. Parents also wanted more providers to use terms which were not offensive toward their children.

Another factor which contributes to how a family copes with autism is the beliefs of the parents. According to Bristol and Schopler (1984), parental beliefs are important to family coping. Family crisis is less likely to occur in cases where the family believes the stressful event is due not to their own inadequacy, but to circumstances outside the family, and the belief that others are also included in these circumstances. Having a good support system is something important to most families of children with autism. This may include immediate and extended family, friends, close neighbors, and support groups that families may be a part of.

Parents also wanted providers and social workers to use current terminology related to ASD when speaking with parents and children. Parents feel more comfortable when providers know current terminology. Having current and future research will be helpful when any services are provided for parents or family with children with autism. This will provide a better understanding of what has been done along with what works and what does not.

With the knowledge of what was identified from the data collected in this study, additional knowledge has been added to the literature. It is the researchers hope that it will stimulate further research that will help parents who are raising children with ASD. This research will hopefully expand into something more and will find further growth by contributing to the literature on supporting parents who are raising children with ASD.

Policy/Practice Recommendations

This section summarizes the policy and practice recommendations that were identified throughout the survey and how each answer emerged from results from this study. The intent of this study was not to criticize others or critique services that have been in place. Instead, this study was supposed to make others more aware of what needs might not have been met for families or parents that need to be addressed or brought to attention in the Minnesota communities involved. This study has shown many needs are still unmet in supporting families raising a child with ASD at home. In addition, it was designed to provide information about current services along with providing current services with advocates, the school system, and also the community and professionals working in the field of social work to better serve parents.

The parents who were surveyed stated the need for better training for providers. This was something that needed to be examined along with more community services for families and parents in more rural areas. Also, parents wanted to see professionals and social workers take part in becoming aware of current services along with using correct terminology when talking to family members about their children/child. Programs with support groups do meet in the area, but these parents would like to see more support group meetings along with a closer distance to the meeting.

Parents also indicated they would like to see more PCA hours for their children/child. This would give parents more time at work or having time to go buy groceries.

Another theme was that parents were noted being heard using recent research along with current terms. Given this, many parents wanted to have support groups closer to home and not an hour way from their hometown. Having providers and social workers using current terms

when speaking with parents and children will help more parents feel comfortable. Having current and future research will be helpful when any services are provided for parents or family with a child with autism. This will provide a better understanding of what has been done along with what works and what does not. According to Dillenburger et al. (2010):

limited financial resources, lack of appropriate services and insufficient support are generally held to contribute to poor prognosis. Social support on its own is not enough. The expertise of those providing support is an important factor in the alleviation of parental stress, in particular in relation to self-efficacy, behavior management and provision of home based care. (p. 14)

With the knowledge of what was identified from the data collected in this study, additional knowledge has been added to the literature. It is the researchers hope that it will stimulate further research that will help parents who are raising children with autism. This data will hopefully expand into something more and will encourage further research.

More research should be gathered to identify even more needs, supports and community resources and to share even more concerns of parents that providers need to be aware of. This information should be presented to relevant professionals along with agencies to provide professionals with continuing education to keep them current with the needs of families raising a child with autism. Using current studies can be used to help provide more ideas to help both families and the providers who help them. With continued research in this area, hopefully more awareness and discussions can develop to better set policies along with providing the correct research needed.

With the research that was being analyzed and data received by the parents, it is this researcher's goal to continue to provide the awareness to parents and other professionals involved about the needs of families with children with autism. In addition, the perceptions

parents in this study had about social services availability has made the researcher more aware of parents raising a child with autism. With the information gained from this study, the researcher will continue to share this knowledge both with parents and providers.

Implications

As reflected in the literature review more research should be gathered to identify more needs, supports and community resources and to share the concerns of parents that providers need to be aware of what autism is. This information should be presented to relevant professionals along with agencies to provide professionals with continuing education to keep them current with the needs of families raising a child with autism. Using current studies can help providers by giving them more ideas to help both families and the providers who help them. With continued research in this area, hopefully more awareness can develop to better set policies along with providing the appropriate research needed. In the study participants spoke of perhaps something “missing” from schools, county and support groups for their child with autism. Parents felt that they needed to become an advocate for their child and to rely on others who have gone through what they have experienced. Because of that they could relate well with other parents.

Looking at autism through the eyes of the six participants highlighted the ways autism may be viewed. Autism may be categorized from other people’s views where the individual may know nothing about what the family or child is going through with this disorder. This study has shown what parents are facing and how we as social workers can view their feelings and thoughts and be able to help parents out when needed.

Implications for Social Work Practice

Social workers must critically question themselves to be sure correct information is being given and to be able to promote appropriate interventions to the best of their ability. The information gained from this study could help social workers better advocate for parents/guardians and care providers. A very insightful study would be to use the information that was found to help advocate for parents/guardians and also care providers. Knowing the information that is needed by parents can also open opportunities for obtaining much needed services.

This author can better advocate for parents whom she may work with in the future with the knowledge which she has gained from researching and writing this thesis. The information which the author is making available to social workers should be of benefit to them when they work with care providers of children with autism. This information should also provide other social workers with a better understanding of autism, since no similar studies have been done on this topic.

The researcher had no knowledge of this particular topic concerning autism having been presented in the past. This gave the researcher a more determined attitude to finish this thesis. This thesis will let parents of children with autism know there is help for the family and child who may have been diagnosed with autism. The need for support is a key role in helping families along with having support from family members and the community.

Information for Diverse/Different Populations

There was not a diverse population of individuals of color in the population of the county in which this study took place. The survey was given in a rural area with limited resources. The

population was mostly female. It would have been beneficial to have had the spouses or significant others answer the questions as well. It would also have been beneficial to have had people of color take the survey.

To improve the study, the author would have liked to have seen a better outcome with individuals of diversity take the survey. The author would have liked more ethnicity in this study. This would have given more diversity and some outcomes may have been different from the current surveys that were done. The author believes more research is to be done on this topic. Having a larger sample and a more diverse sample population, it may assist in giving a deeper look at what autism really is and how the parents can better the services and support they need in their own community.

This study could also spark the debate on a national level with promoting more awareness about autism. As a result, smaller communities might receive more funding for better resources including staff training. Having staff that received more training would help parents feel more comfortable with personnel who are working with their kids.

Limitations of the Study

As mentioned before the lack of diversity was evident in the study sample, as all six participants identified themselves as Caucasian females. To obtain a well-rounded survey, having a more diverse population would have been a key factor in discovering how individuals of color may show new outcomes with their children who have autism. This study sample may have used family systems theory as connection pieces for participants to describe their current family situation. Additionally, the views were all female and heterosexual. As a result, it is unknown if these women were married or had a significant other (only if they listed their

preference). It would have been interesting to have the male perspective about their views on autism and how the dad or significant other is raising the child as well. The researcher would have liked to expand the survey to have the sample size allow more opportunity for diversity but time and constraints of the research project limited the sample size to six.

Findings Different/Similar to Studies Cited in the Review of the Literature

When writing my Literature Review, I was made aware of needed services in rural areas especially for children with autism and their parents/guardians. Having more resources along with supportive services and funding can contribute to better and more favorable outcomes for these individuals.

Rural dwellers experience disadvantages compared to those who live in urban environments. The key challenges to obtaining resources and services in remote areas are transportation, lack of local support, isolation, few employment opportunities, geography, and limited financial resources. These challenges are compounded when an individual who lives in a rural area also has a disability...two key variables that affect service delivery to remote locations are population density and topography. (Symon, 2001, p. 162)

With the research that was analyzed using data by the parents who were surveyed, it is this researcher's goal to continue to provide the awareness to parents and other professionals involved about the needs of families with children with autism. Having knowledge about the impact on families of raising a child with autism can help these families. With the perceptions parents in this study had about social services availability, this study has made the researcher more aware of difficulties of parents raising a child with autism. With this knowledge, the researcher will continue to share this knowledge both with parents and providers.

Summary

When parenting any child/children with a disability, it may be challenging but yet rewarding at the same time. Parents may feel overwhelmed when needed supports are not there. In addition, the demands of being the main provider for their child/children can be a challenge. Knowing that all parents with a child with autism face the same challenging tasks, they may feel more comfortable knowing others are also experiencing the same thoughts and feelings. With proper supports and services for families raising a child with autism, as their child grows and develops into an adult, many parents can feel the satisfaction that they were able to help and be involved in the growth and development of their child.

The author discovered that participants were enthusiastic about the opportunity to discuss their family, life, and stories. All the participants were proactive in finding ways to better their family including their child with autism. This has helped parents know and learn more about their child. Participants were also happy to share new ways they created to help their child learn better in school, at home, or in the community.

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Appendix A: IRB Approval Letters

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December 4, 2012

Lisa Holmquist-Arndt
St. Cloud State University
720 4th Ave South
St. Cloud MN 56301

Dear Ms. Holmquist-Arndt,

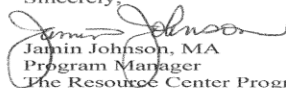
Welcome to working with families! We work closely with many social workers and regional families. Together, we all make a positive difference in the lives of children, teens and adults with life challenges/disabilities.

It is The Resource Center Program Board Members' understanding that as a student at St. Cloud State University working to acquire your Master of Social Work degree, you wish to conduct a research study to explore the Social Service Supports and Services for families raising children with Autism Spectrum Disorders (ASD).

We understand that this research project will involve inviting parents and/or guardians of children who have been identified as having ASD to fill out an optional survey. Our ADHD/Autism Coordinator has agreed to allow you to hand out your information at her December networking group meeting. We understand that respondents and children will not be identified in this process or your final report of findings.

As we continually look for ways to help improve people's lives, we look forward to receiving a copy of your final thesis. Its information will prove to be informative. Thanks for all you do-- and best wishes as you crunch the data!

Sincerely,


Jamin Johnson, MA
Program Manager
The Resource Center Program
1300 22nd St. SW
Willmar, MN 56201
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EEO/AA



Appendix B: Sample Cover Letter

Support for Autistic Children and Parents Study Implied Informed Consent

You are invited to participate in this study to determine if any supports within the social services to parents that are raising a child with an autism spectrum disorder in the Willmar community. You were selected as a possible participant because you are a user of The Resource Center. This research project is being conducted by Lisa Arndt, for St. Cloud State Graduate School, and The Resource Center staff.

Background Information and Purpose

The purpose of this study is to enhance our current support services and perhaps work to strengthen the ones that already are in place.

Procedures

If you choose to participate in the study, you will be asked to complete the one page survey which is completely anonymous so no one will be able to identify a specific individual's form. It's important that we have as many people as possible to complete.

Risks

There are no foreseeable risks with participation in this study.

Benefits

The questions on this survey were developed by reviewing the research on Autistic children and identifying the factors that have been found to be important. It's our hope that the information we gain will help us improve our current student support services and perhaps work to strengthen the ones that already exist. This information may be fairly specific to an individual. Because of this, the data will only be examined by Lisa Arndt.

Confidentiality

I realize that due to the number of parents, some of the information may be fairly specific to an individual. Because of this the data will only be examined by researcher Lisa Arndt. Your information will be confidential and no answers that could identify a specific individual will be used.

Research Results

If you are interested in learning of the survey, feel free to contact The Resource Center staff at or you also have a copy provided for you by your request if wanted.

Contact Information

If you have any additional questions please contact the researcher, Lisa Arndt or Dr. Sandra Chesborough at: sjchesborough@stcloudstate.edu

Voluntary Participation/Withdrawal

Participation is voluntary. Your decision whether or not to participate will not affect your current or future relations with The Resource Center. If you decide to fill out the survey and there are any questions you are not comfortable answering, you do not need to answer the questions. We ask you to please remember this information is confidential and is designed to help us serve your family better. If you decide to participate, you are free to withdraw at any time without penalty.

Appendix C: Sample Demographic Questionnaire

Parents Perceptions of County Social Service Supports and Services for Families Raising a Child/ren with Autism Spectrum Disorders (ASD)

Participant Demographics

1. Are you a parent of a child/ren with an Autism Spectrum Disorder (ASD)?

Yes No

2. How many children are you parenting that have an Autism Spectrum Disorder (ASD) and what is their current age(s)?

Number of children with diagnosis of ASD

Current Age(s)

3. Is your child/ren diagnosed with an Autism Spectrum Disorder?

Yes No

If yes, please indicate what their diagnosis is below and the age when they were diagnosed.

Diagnosis

Age Diagnosed

- Autistic disorder (also called “classic” autism)
- Asperger Syndrome
- Pervasive Developmental Disorder Not Otherwise Specified (or atypical autism)
- Childhood Disintegrative Disorder
- Rett Syndrome
- Other (please specify): _____

4. Has your family used county social services and/or supports to assist your family in raising your child/ren with an Autism Spectrum Disorder?

Yes

No

5. Does your family use other formal/informal services and supports to assist your family in raising your child/ren with an Autism Spectrum Disorder (such as special education school services, community supports, family and friends)?

Yes

No

If yes, please note what services and supports you use and how these are beneficial to your family?

Appendix D: Parent Survey

1. What social services/supports have been offered by a county social service agency/professional and what services/supports did you choose to use to support your efforts to raise your child/ren with an Autism Spectrum Disorder (ASD)?
 - A. Offered but didn't use (please feel free to note why):

 - B. Offered and used (please feel free to note what you found helpful/not helpful):

2. Are there other county social service supports and/or services that you wish were offered or available? What would these services ideally provide and how would they benefit your child/ren and/or family?

3. Do you have any suggestions to improve or enhance county social services being provided to families raising children with Autism Spectrum Disorders (ASD)?

4. Is there anything else you would like to share in regards to parenting or raising a child with an Autism Spectrum Disorder (ASD)?