

A Needs Assessment of Autism-Related Services and Supports in Umatilla County, Oregon

Jessica M. McCallister

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Dissertation.com
Boca Raton, Florida
USA • 2010

ISBN-10: 1-59942-348-0
ISBN-13: 978-1-59942-348-7

A Thesis Presented to the Faculty of the
Wilma Hepker School of Social Work and Sociology

Walla Walla University

In Partial Fulfillment of the Requirements
of the Degree of

MASTER OF SOCIAL WORK

By

Jessica M. McCallister

June 2010

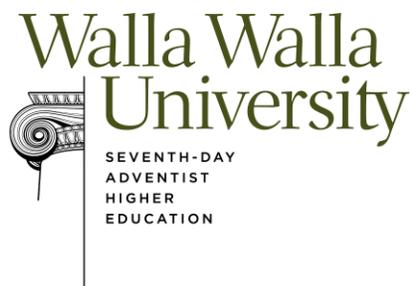
Under the guidance and approval of the committee, and approved by all its members, this thesis has been accepted in partial fulfillment of the requirements of the degree.

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ACKNOWLEDGMENTS

I want to express sincere appreciation to Professor Heather Vonderfecht, Ph.D for her profound patience and commitment to helping me succeed in preparing this thesis. Heather has guided me through many struggles and frustrating moments throughout my last two years under her instruction. She has always been available with an open heart and encouraging sentiments. She has never failed to provide timely words of wisdom to me and has always, from day one, believed in my ability to write this project. My time at Walla Walla University will always be remembered because of Heather's commitment to my learning.

I also want to thank Lana Martin, PhD and Cheris Brewer Current, PhD for their assistance in the preparation of this manuscript and their wonderful guidance in course work and my learning.

Finally, I want to acknowledge my husband, Charlie McCallister, for the many years of patience and support he has offered me during my studies, from the beginning of my bachelor degree at the University of Phoenix all the way through the completion of my master degree at Walla Walla University. He has spent many lonely, bored nights sitting on the couch watching me burn the midnight oil and was always considerate in listening to me read papers to him. He has been my rock. I love you Charlie.

Jessica McCallister

Abstract

Through the Department of Human Services in the State of Oregon, children with autism can access varying services, although, in the rural communities of Oregon, the delivery of those services becomes difficult. Rural availability is affected as members of the rural communities are less knowledgeable of the practices involved in administering effective services, instruction, and interventions to children with developmental disorders. The aim of this thesis is to identify areas within Umatilla County, Oregon where services and support systems are in place, or not in place. The population with whom this study was conducted includes individuals that have recent or past experience or relationships with children with autism living in Umatilla County, Oregon. The participants were asked to complete surveys consisting of questions relating to services they currently or in the past have provided to children with autism, questions relating to the delivery of those services, and questions relating to what type of support services they know of or have been involved in regarding children with autism or their family members. Data acquired addressed the already existing services and support systems and identify areas within the region where possible gaps or weaknesses exist, thus aiding in important knowledge and groundbreaking ideas into the need of autism-related services and supports in Umatilla County, Oregon.

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A Needs Assessment of Autism-Related Services and Supports in Umatilla County, Oregon

Providing interventions and services to children has become an international trend in the past few decades, with large focus toward children with special needs. Currently, efforts are focused on identifying particular areas including educational, emotional, and social development. With the expanding focus on children's needs throughout the world, a specific developmental disorder has been identified as paramount in research; Autism. Located in the United States, the National Institute of Health (NIH) has become the instrumental agency for conducting autism research. The NIH is the primary federal agency for conducting and supporting basic, clinical and translational medical research, and it investigates the causes, treatments, and cures for both common and rare diseases (National Institute of Health, 2009).

Although the NIH is the leading federal agency conducting research in the field of autism, each state is responsible for delivering services to children with autism. Even though autism is a disability, each state has different eligibility criteria for each disability category. As a result, the proportion of children with a particular disability differs from state to state (Autism Fights, 2009). For example, a child residing in the state of Utah may receive varying benefits and support through the Utah Department of Disabilities; alternatively a child of similar disabled traits may receive fewer benefits and support from the Texas Department of Disabilities, based on the availability of services from the State of Texas. While each state operates their delivery of services differently, children with Autism face the same needs and struggles nationwide.

In the state of Oregon, the Seniors and Peoples with Disabilities Division within the Department of Human Services contracts with each County in Oregon to provide a variety of services to individuals with developmental disabilities through local Community Developmental

Disabilities Programs (CDDP). Each CDDP is generally part of the larger county Community Mental Health Program, and serves as the “gateway” to developmental disability services within the state of Oregon (Department of Human Services, 2009). Through the Department of Human Services, children with autism can access varying amounts of services, although, in the rural communities of Oregon, the delivery of those services becomes difficult. Rural availability is affected as members of the rural communities are less knowledgeable of the practices involved in administering effective services, instruction, and interventions to children with developmental disorders. Although the last decade has seen an expansion in the knowledge of effective instructional practices for students with Autism, controversy exists among researchers, program developers, educators, parents, attorneys, advocates, and the media regarding the appropriateness of specific strategies (e.g., Gresham, Beebe Frankengerger, & MacMillan, 1999; Helfin & Simpson, 1998b; Hurth, Shaw, Iseman, Whaley, & Rogers, 1999).

The federal government requires every state to provide children with services, supports, and education. The primary pathway to delivering services to children with special needs is through state disability agencies, although the delivery of services to children with autism has become difficult. Through a recent study by the Department of Human Services called the Oregon Autism Project, a key area of concern relates to “social services delivery.” Within the social service delivery of autism services, the Oregon Autism Project identified that services are designed for individuals with physical or cognitive disabilities, but those services have often failed to address the unique environmental, behavioral, communication, or sensory considerations that make autism a distinct condition (Department of Human Services, 2009). Whereas a specific recommendation from the Oregon Autism Project emphasizes to improve the

social services delivery by promoting educating for and to employees about autism, the recommendation does not discuss how to promote education or interest within the rural communities of Oregon about autism. To enhance the delivery of services to children of autism and families of children with autism, communities across the nation have come together to form action committees, support groups, and organizations to better serve those children and families in need. Unfortunately, rural communities in Eastern Oregon have struggled to build networks of services and supports beyond what the Department of Human Services offers. For example, in the larger cities and communities in western Oregon, hospitals, institutes, research centers, universities, associations, and divergent support groups for families of children with autism are bountiful. Unfortunately, the eastern side of the state of Oregon does not have the population similar to the west side, and the more thinly spread population and greater distances over sometimes poor quality roads leads/causes the eastern communities to have a substantial decrease in the prevalence, variety, or interest of delivering services to children and families of children with autism.

Statement of the Problem

The challenges presently associated regarding working with children and families coping with autism are broad, although through an analysis of the relevant literature three areas present as clear: lack of appropriate interventions and services to children with autism, insufficient delivery of services to children with autism, and a need for more support services to families of children with autism. Communities working with children with autism strain to fully understand how to deliver accurate and effective interventions and services. As Jacobson and Mulick (2000) suggest, the lack of effective and coordinated care systems for children with autism manifests in

high levels of stress for families. Additionally, Dunn and Sivberg (2001) also agree that the high levels of stress, social isolation, and marital dissatisfaction among families of children with autism present strain in communities and educational systems. As varying literature discusses, these three broad areas of providing to children and families of children with autism are the overarching concerns focused on effective delivery of interventions and support.

Purpose of the Study

Purpose statement. The purpose of this study will be to identify the areas within the communities of Umatilla County, Oregon in need of enhanced supports and services to children with autism and their families. Additionally, this thesis will provide recommendations in relation to enhancing already existing autism-related services and suggest potentially new services.

Rationale for the study. In Umatilla County, Oregon, there are approximately 150 school-aged children diagnosed with autism. Many other children who have not reached school-age often go undiagnosed. Factors leading to children being undiagnosed vary: no access to school district services (due to the age of the child), families being unaware of the services offered from their community, or families who are overwhelmed with behavioral issues their child exhibits, all the while, not realizing their child may have autism or another neurological or pervasive developmental disorder. Regardless of the factors leading to children being undiagnosed or families not knowing how to access services for their children, a community must educate and support families with children with autism. Without a support network or educational avenues for learning about autism, children and families of children with autism struggle to maintain healthy families and connections within the community. Oftentimes, undiagnosed children reach school-age and consequently, families become overwhelmed with

behaviors and characteristics of their children as they age. If supports and services are unavailable or unattainable, children and families of children struggle immensely. Finally, to substantiate a rationale to identify, explore, and suggest recommendations of how to improve the access and delivery of autism-related services in Umatilla County, Oregon, a survey of the existing services and supports will be conducted.

Description of the study. To identify areas within Umatilla County, Oregon that relate to providing services to children with autism, delivering services to children with autism, and identifying the existing support services to families of children with autism, this researcher plans to administer surveys to members of the community. The surveys will be administered to parents, educators, caregivers, child welfare caseworkers, disability caseworkers, and other professionals in the community that have had or currently have a relationship with a child with autism. The surveys will ask specific questions relating to what community the participant mostly associates with children with autism, how many children with autism has the participant known in the last 12 months, and what service/s the participants has provided to a child with autism, either through their work or as a parent or provider. Additional questions will include demographic questions and what type of support services and training has the participant known of or been involved with.

Expected outcomes. As a result of identifying areas within the community that provide services and supports to children of autism and families of children with autism, recognition and knowledge of gaps and weaknesses are expected to be identified that will provide indications of how to enhance the delivery of services and supports in Umatilla County, Oregon.

Research Questions

- *What services are offered to children and families of children with autism in Umatilla County, Oregon?*
- *How are the services being offered to children and families of children with autism delivered in Umatilla County, Oregon? Are the media, schools, networks, or organizations involved in the delivery? If so, how are services being delivered, and if not, what would benefit the delivery of current services and supports?*
- *Based on the findings of the research, what are the recommendations on how to improve the three problems areas associated with providing services, delivery service, and support services to children and families of children with autism in Umatilla County, Oregon?*

Significance of the Study

The short and long-term benefits to the participants of this study could be great or significant in relation to the information attained in identifying the needs of the community for services to children with autism and families of children with autism. The participants will play a direct role in providing perspectives and concerns for systems of autism-related services and supports in Umatilla County, Oregon. Although a larger scale study has been conducted by the Oregon Autism Project that identified state-wide problem areas of autism-related services, no study has specifically targeted Umatilla County, Oregon to this researcher's knowledge. The data gathered from this study could prove significant information for funding opportunities related to program development, program enhancement, and community interest in developing supportive and educational networks for children with autism and families of children with autism.

Limitations

The design of this study is conducted in a fashion that provides as many community members as possible the ability to contribute their knowledge, experiences, and concerns related to providing autism-related services in Umatilla County, Oregon. In general terms, a limitation is a flaw or weakness in the study that affects the internal validity and the external validity of the results (Bui, 2009). Whereas careful thought and consideration went into developing the design of this study, limitations exist that include (not yet fully developed this thought yet)

Internal validity. Due to the many groups of participants that will be accessed for this study, the internal validity is weak in regard to the many variables involved. This design is developed as a needs assessment; therefore, the internal validity will be difficult to determine as in relation to only the sample population from which will be contacted. Understandably, this researcher is unable to reach every member of the community involved with children with autism.

External validity Possible external validity flaws of the research design are related to time constraints. This study requires completion within three academic quarters, thus response time before all the groups of participants will be challenging for this researcher.

Ethical Considerations

The procedures in this study include ensuring the research is conducted ethically. This researcher is required to submit the study in the form of a proposal to the Walla Walla University Institutional Review Board (IRB) prior to conducting the research to ensure the design does not pose a risk to the participants. Included in the IRB review process, this researcher will provide the board with a copy of the informed consent, will have obtained preliminary permission from

agencies to access participants, and submit an application outlining the methods section to ensure compliance in accessing data. The researcher will include a blank copy of all the surveys and consent form to the IRB as well as include forms in the Appendix at the end of the completed research project.

Literature Review

The study of autism has become a considerable topic around the world, with emphasis on the etiology of the disorder, behavioral interventions, proper diagnosis, impact on families of children with autism, and educational programming for children with autism. As research has suggested, services for individuals with autism spectrum disorders (ASD) have been described as limited, unavailable, difficult to obtain, inappropriate, inaccessible, and costly (Dymond & Myran, 2002; Fong, Wilgosh, & Sobsey, 1993; Kohler, 1999; Little, 2003; Sperry, Whaley, Shaw, & Brame, 1999; Starr, Foy, & Cramer, 2001; Whitaker, 2002). No one area of studying autism is less important than the other, thus bridging and integrating all areas of autism into one community are challenging, but not impossible. Notably, parents often struggle to identify and obtain services (e.g., respite care, speech therapy, and afterschool care) from multiple agencies and organizations that have different eligibility criteria (Dymond, Gilson & Myran, 2007). Consequently, community efforts to provide services to children with autism, deliver services to children with autism, and provide access and support to families of children with autism oftentimes linger for years or do not flourish at all. Furthermore because many young people with autism experience difficulty in expressing their strengths, weaknesses, and needs for support, parents are often the primary source of information about their child's needs (Dymond et al. 2007). Whereas the study of autism is vast, being able to integrate supports and services into a community is challenging, and at times, families become disheartened when they feel their community is not supportive or encouraging to provide the services and support their child needs.

The following literature review will discuss many concepts related to providing services to children and families of children with autism. The first section will deliver information explaining what the autism spectrum disorder is, the history of the disorder, and who the pioneers of autism research are. In the second section, a review of the literature will reveal the most effective interventions and services administered to children with autism. In the third section, emphasis is placed on identifying areas within the research that discuss how services are provided to children with autism. This section will identify the most effective avenues of administering services to children including through programs, agencies, and communities. The fourth section will focus on identifying the need to provide support services to families of children with autism. In this section, examples of existing support programs will be addressed including the importance of providing supports to families of children with autism. In the final section, discussion will emerge relating to how the role of how social work can contribute to a community need to provide for children and families of children with autism. The literature review will provide a thorough analysis of the relevant research conducted in the field of autism relating to the three problem areas identified in this thesis: 1) services to children with autism, 2) delivering interventions and services to children with autism, and 3) support services to families of children with autism.

Autism Spectrum Disorder

What is Autism?

Many explanations exist in describing what autism spectrum disorder is. Following are the most significant terminologies used throughout the research literature and are derived from the major research institutes, societies, and organizations across the United States.

National Institute of Health. Autism spectrum disorder (ASD) is a range of complex neurodevelopment disorders, characterized by social impairments, communication difficulties, and restricted, repetitive, and stereotyped patterns of behavior. Autistic disorder, sometimes called autism or classical ASD, is the most severe form of ASD, while other conditions along the spectrum include a milder form known as Asperger's syndrome, the rare condition called Rett syndrome, and childhood disintegrative disorder and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS) (National Institute of Neurological Disorders and Stroke, 2009).

Autism Research Institute. Autism is a severe developmental disorder that begins at birth or within the first two-and-a-half years of life. Most autistic children are perfectly normal in appearance, but spend their time engaged in puzzling and disturbing behaviors which are markedly different from those of typical children. Less severe cases may be diagnosed with Pervasive Developmental Disorder (PDD) or with Asperger's Syndrome (these children typically have normal speech, but they have many "autistic" social and behavioral problems) (Autism Research Institute, 2008).

Autism Society of America. Autism is a complex developmental disability that typically appears during the first two years of life and is the result of a neurological disorder that affects the functioning of the brain, impacting development in the areas of social interaction and communication skills. Both children and adults on the autism spectrum typically show difficulties in verbal and nonverbal communication, social interactions, and leisure or play activities. Autism is one of five disorders that fall under the umbrella of Pervasive Developmental Disorders (PDD), a category of neurological disorders

characterized by “severe and pervasive impairment in several areas of development (Autism Society of America, 2009).”

Autism Speaks Organization. Autism is a general term used to describe a group of complex developmental brain disorders known as Pervasive Developmental Disorders (PDD). The other pervasive developmental disorders are PDD-NOS (Pervasive Developmental Disorder – Not Otherwise Specified), Asperger's Syndrome, Rett Syndrome and Childhood Disintegrative Disorder. Many parents and professionals refer to this group as Autism Spectrum Disorders (Autism Speaks Organization, 2009).

As one can detect, many terminologies exist regarding what autism spectrum disorder is.

There are many ideas as to the correct terminology of autism including: *complex neurodevelopment disorder, complex developmental disability, and complex developmental brain disability*. While varying terminologies are used to describe autism, an agreement seems to be apparent in that autism includes a variety of characteristics including social impairments, difficulty in communication, and a display of disturbing behaviors. Although many terminologies exist in describing autism spectrum disorder, The *Diagnostic and Statistical Manual of Mental Disorders* (DSM) is the standard classification of mental disorders used by mental health professionals in the United States (American Psychiatric Association, 2009) to diagnose children with autism.

Following is the criteria developed by the American Psychiatric Association to diagnose children with autism:

Diagnostic and Statistical Manual, Fourth Edition, Text Revision

A total of six (or more) items from heading (A), (B), and (C), with at least two from (A), and one each from (B) and (C):

(A) Qualitative impairment in social interaction, as manifested by at least two of the following:

- Marked impairments in the use of multiple nonverbal behaviors such as eye-to-eye gaze, facial expression, body posture, and gestures to regulate social interaction.
- Failure to develop peer relationships appropriate to developmental level.
- A lack of spontaneous seeking to share enjoyment, interests, or achievements with other people, (e.g., by a lack of showing, bringing, or pointing out objects of interest to other people).
- A lack of social or emotional reciprocity.

(B) Qualitative impairments in communication as manifested by at least one of the following:

- Delay in or total lack of, the development of spoken language (not accompanied by an attempt to compensate through alternative modes of communication such as gesture or mime).
- In individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others.
- Stereotyped and repetitive use of language or idiosyncratic language.

- Lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level.

(C) Restricted repetitive and stereotyped patterns of behavior, interests and activities, as manifested by at least two of the following:

- Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus.
- Apparently inflexible adherence to specific, nonfunctional routines or rituals.
- Stereotyped and repetitive motor mannerisms (e.g. Hand or finger flapping or twisting, or complex whole-body movements).
- Persistent preoccupation with parts of objects. (Diagnostic and Statistical Manual, Fourth Edition, Text Revision, 2000).

As autism has been defined through different organizations, associations, and societies, it is clear that the term “autism” relates to a disorder that involves many challenges a child experiences in their everyday life. Being diagnosed with autism includes having careful, medical and psychological attention paid to many facets in a child’s behavioral, cognitive, and social functioning processes. While a more understood definition in the 21st century, in the latter part of the 19thth century, autism was not as clearly understood. Following is a brief history of the development of autism, including prominent pioneers of the discovery of the disorder.

History of Autism

Leo Kanner. Leo Kanner was born in Vienna, Germany in 1894 and was said to be the primary person to discover the autistic child. Leo Kanner (1943) in Baltimore, USA, described 11 children with ‘early infantile autism’ in his seminal paper ‘*Autistic disturbances of affective*

contact'. Kanner's seminal paper became known around the world, inspiring the overwhelming interest in determining the etiology of the autistic disorder. Kanner defined autism narrowly and was dismayed by its widening "almost over night" to include children with isolated autistic symptoms on the basis of brain damage and mental retardation (Wolff, 2004). Because of the narrow view Kanner developed of children's characteristics that qualified them as autistic, the number of children diagnosed as autistic exploded in the 1950s and 1960s. The terms associated with being autistic increased the diagnoses of children with the disorder. Many believed if their child had a "behavioral" issue, they were autistic. According to Kanner, in the 1950s the country was populated by a multitude of autistic children (Kanner, 1973). Moreover, in the 1950s and 1960s, especially in the United States, schizophrenia was everywhere, and in children it included autism (Barron & Cohen, 2002). Throughout the latter part of the 20th century, the causes and effective treatment of autism became more clearly defined as new technology emerged and psychiatrists, clinicians, and educators became more fully aware of all the exquisite characteristics of the disorder.

Pioneers of Autism Research

Although Kanner is considered the pioneer whom discovered autism, other pioneers have risen after Kanner's discovery. Through an analysis of the literature and extensive investigation into the development and research of autism, two people have emerged as prominent in contributing to the advancement of autism; Dr. Bernard Rimland, PhD. and Dr. Stephen M. Edelson, PhD.

Bernard Rimland, PhD. Bernard Rimland was born in Ohio in 1928. Rimland studied psychology at San Diego State University and completed his doctoral work in experimental