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School Social Workers' Role in Supporting Parents of a Child with Autism

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School Social Workers' Role in Supporting Parents of a Child with Autism

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MSW Clinical Research Paper

Presented to the Faculty of the School of Social Work St. Catherine University and the University of St. Thomas St. Paul, Minnesota in Partial fulfillment of the Requirements for the Degree of

Master of Social Work

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The Clinical Research Project is a graduation requirement for MSW students at St. Catherine University/University of St. Thomas School of Social Work in St. Paul, Minnesota and is conducted within a nine-month time frame to demonstrate facility with basic social research methods. Students must independently conceptualize a research problem, formulate a research design that is approved by a research committee and the university Institutional Review Board, implement the project, and publicly present the findings of the study. This project is neither a Master's thesis nor a dissertation.

Abstract

This quantitative research study explored the role of the school social worker in supporting parents of a child with autism spectrum disorder (ASD). Surveys were emailed to members of the Minnesota School Social Workers Association. Participants were asked to complete the survey if they worked as a school social worker and supported students with ASD. The survey investigated the impact of an ASD diagnosis on the parental stress and what role school social workers had in supporting parents' needs. The objective of this study was to gain a better understanding of the school social workers' role and identify what supports are being utilized and which are not.

The three most common supports were connecting parents to community resources, acting as a liaison between school and home and emotional support. Respondents reported parents most frequently report stress relating to behavior, educational needs and lack of resources. Some respondents reported certain areas of stress in which they did not feel it was their place to provide supports such as parent support groups.

These findings also uncover implications for future research. There is a need for more detailed research investigating the role school social workers have in supporting parents of a child with ASD. It is important to identify what stressors these parents are experiencing in order to develop best practice and interventions.

Keywords: Autism, School Social Workers, Parental Stress, Support

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School Social Workers Role in Supporting Parents' with a Child with Autism

Autism Spectrum Disorder (ASD) is a lifelong neurodevelopmental disorder that presents within a range of complex developmental disorders that are characterized by difficulties in social interaction, verbal and nonverbal communication and repetitive behaviors (Rezendes & Scarpa, 2011). According to the *Diagnostic & Statistical Manual of Mental Disorders* IV-TR (DSM-IV-TR; American Psychiatric Association, 2000), ASD includes Autistic Disorder, Rett syndrome, Childhood Disintegrative Disorder, Pervasive Developmental Disorder-not otherwise specified (PDD-NOS) and Asperger syndrome.[1]

Children are being diagnosed with ASD at a growth rate of 1.148% each year, which is the fastest growing rate of any developmental disability (Autism Society, 2014) and affects as many as one in every 110 children (Rezendez & Scarpa, 2011). Boys are diagnosed with ASD three to four times more frequently than girls, with as many as one in 88 children being diagnosed today (What Is Autism?, 2014). With ASD on the rise, it is important to understand how the disorder affects families and what the family needs are regarding supportive services and resources.

In general, social workers encounter children with ASD in a variety of areas including schools, daycare, child welfare settings, social service organizations, hospitals, clinics and mental health treatment facilities (Dababnah et al., 2010). Among the several professions who work with children with ASD, social workers have moved to the forefront in the areas of case management, community interaction and social skills

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[1] In 2014, the DSM-V was released with revisions made to diagnosing criteria for Autism Spectrum Disorder. Since the newest edition was recently released, this research will focus on prior practice namely before the DSM-V, therefore this study will reference the DSM-IV and diagnostic criteria.

training (Comegys & Guggemos, 2014). However, there is limited research on the role of the school social worker and the support provided to children with ASD and their families.

More often than not, children with autism require individualized support services throughout the formal educational process. School social workers are often part of the goal planning process. They are often responsible for creating and supporting an Individualized Educational Plan (IEP) for the child. In addition, parents of children with an autism diagnosis often need additional support, which the school social worker has the opportunity to provide. Parents are often in need of emotional support, as well as resources within the school system and community. A problem with existing research, however, is the paucity of examination and understanding the role of the social worker in serving parents with children who have ASD. Additionally, there is a deficit in the research on how well social workers are meeting the needs of parents (Newsome, 2000). In hopes of bridging this gap in services and research, using an ecological perspective as a guide, this paper examines the school social workers' role in supporting parents with a child with an ASD diagnosis. With school social workers being employed by the school district and the client being the student with Autism, there is a question that must be addressed, what is the role of the school social worker in supporting parents with a child with an ASD diagnosis?

Literature Review

With the prevalence of ASD on the rise, it is important to recognize the impact of an autism diagnosis on parents and their stress levels. Stressors, as described in the literature, are variables that place additional demands upon the caregiver or family unit. Frequently occurring child-related stressors among parents of children with ASD include

ambiguous loss, reactions of others, marital stress, lack of resources, behavioral problems and special education accommodations. This paper will discuss the common stressors parents with a child with ASD experience and the role a school social worker has in supporting these stressors.

When parents are initially informed their child has an ASD diagnosis, they often experience ambiguous loss and must cope with reactions of family members and outsiders. The vision of a life with a 'normal' child is changed once a diagnosis is reached. Parents must learn to recognize what the ASD diagnosis means to them, as well as those around them including other family members and friends. Family members and friends can often be a strong resource for support. However, family can also have difficulty understanding the diagnosis, leading to feelings of misunderstanding and isolation. Support groups and other community resources serve as strong supports for parents in feeling understood and validated in their journey with their child who has ASD. Additionally, parents with a child who has ASD, experience higher levels of marital stress and financial constraints in obtaining resources (Altiere & Von Kluge, 2009; Borbst, Clopton & Henrick, 2009; Gray, 2002; Hartley et al., 2012; Hutton & Caron, 2005; Lyons et al., 2009; Meirsschaut, Roeyers & Warrren, 2010; Neely, Amatea, Echebarria-Doan & Tanned, 2012; O'Brien, 2007; Ramisch, 2012; Risdale & Singer, 2004; Sobsey, 2004; Weiss & Lunsky, 2011).

Often children with an ASD diagnosis will need special accommodations within the school setting. School social workers often are involved in setting up these services and work to support the student in his or her educational goals. School social workers can also serve as a support for parents in coping with stressors relating to educational goals, as

well as external stress factors. Support can be provided through education pertaining to

the ASD diagnosis, as well as providing parents with resources in the community to cope

with the stresses that often accompany having a child with this diagnosis. The ecological

framework serves as a helpful lens in exploring this scenario.

Conceptual Framework

In the interest of creating perspective and placing this research in context, a

conceptual framework of the ecological model will be used. While working in educational

systems, school social workers encounter several challenging situations. Clancy (1995)

states since the turn of the twentieth century school social workers have been attempting

to determine the value of effective practice. The ecological framework is a model that is a

helpful lens for school social workers, as this perspective provides a way to understand

human diversity and clarifies the relationship between humans, their environment and the

transactions that exist between the two (Forte, 2007, p.123). Clancy (1995) states that the

ecological perspective defines effective practices as interventions that occur within all

system levels (microsystems, mesosystems and macrosystems). The National Association

of Social Workers (2002) defines the ecological perspective for school social workers as

the relations between the student, family and environment. The ecosystems perspective

allows social workers to identify the functioning of an individual while taking into

account his or her environment and the related systems surrounding him or her (Eveslage,

2012). In the context of the ecological perspective, stress occurs when there is a mismatch

between person and environment and the ability to cope and adapt to life stressors (Forte,

2007). This experience is mirrored when parents with children with Autism are unable to

effectively cope and adapt with the surrounding stressors that accompany the disorder.

Social workers can assist parents in the process of parenting the child with Autism by identifying coping strategies to deal with the disorder.

The child's environment includes many systems that both interact and affect each other on various levels. Systems become imbalanced as changes occur in the environment, individual development and life events (Garrett, 2007). There are many systems that have an effect on a child with ASD including the child's family, peers, school, medical team and mental health professionals (VanBergeijk & Shtayermman, 2006). Social workers are found to be most effective when intervening simultaneously in more than one system (Dababnah et al., 2011).

The ecological framework lens allows for internal and external systems and relationships to be examined and how those impact the role of the social worker within the context of this research (Eveslage, 2012). The roles of the school social worker include collaboration with the multidisciplinary team, input in the assessment process, supporting teachers and the family and educating family members, teacher and peers about ASD. In addition, school social workers are tasked with serving as an advocate for policy changes that would benefit this population (Eveslage, 2012).

Defining Autism Spectrum Disorder

As noted, autism is a pervasive developmental disorder that is highly complex and variable in presentation and manifestation (NetLibrary & Berkell Zager, 2005). This devastating disability is found across all socio-economic and racial groups (Bloch, 2014). The key characteristic of autism is the neurodevelopmental impairment and presence of a unique deficit in the nature and quality of social and communicative development, as well

as behavior (NetLibrary & Berkell Zager, 2005; Shtayermann, 2013). It is this behavior

deficit that differentiates autism from other neurodevelopmental conditions such as mental

retardation and specific learning disabilities (Berkel Zager, 2005).

The symptoms of this disorder range from mild to severe impairment. Therefore,

this disability is classified within a "spectrum." The severity of these impairments dictates

the seriousness of the disorder and level of care needed for that individual. The diagnostic

criteria for ASD is defined in the *Diagnostic & Statistical Manual of Mental Disorders

IV-TR* (American Psychiatric Association, 2000) as follows (for official DSM-IV-TR

definitions, see Appendix A):

I. 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. 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.

II. Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years:

   (A) Social interaction

   (B) Language used in social communication

   (C) Symbolic or imaginative play

   Diagnosing ASD can be very difficult as there are no medical exams to confirm the disorder. Doctors or other professionals identifying the diagnosis must recognize variance in behaviors and development and identify abnormalities from a normal

developing child. Bloch (2014) advises that a diagnosis can be reliably confirmed in the

age range of 18-24 months. While Lord et al. (2006) believes by the age of two, a

diagnosis by a seasoned professional can be considered reliable. However, many children

are not diagnosed until a much older age. For these children, the delay may result in not

receiving much-needed help and support (Lord et al., 2014).

There are two parts to diagnosing a child with ASD, including a developmental

screening and comprehensive diagnostic evaluation (Lord et al., 2006). The

developmental screening is a short test to identify if the child is learning basic skills for

his/her age group or if there are any deficits. During this screening, the doctor may acquire

information from the parents or observe the child in play to see how s/he learns, speaks,

behaves and moves (Lord et al., 2006). A deficit in any of these areas could signal a

problem. Lord et al. (2006) advise all children should be screened for developmental

delays and disabilities during regular wellness doctor visits at nine months, eighteen

months and between twenty-four and thirty months. Additional screening may be

necessary for children with a higher risk of ASD, such as having a sibling who has ASD.

If the doctor identifies any deficits or areas of concern in the above screening a

comprehensive diagnostic evaluation is necessary.

The comprehensive diagnostic evaluation is the second step of the diagnosing

process. In some cases, the primary doctor may decide to refer the child and family to a

specialist for further assessment. Professionals who may conduct this assessment include

developmental pediatricians and pediatric neurologists (Lord et al., 2006).

Diagnosis & Impact

While each family situation is unique, parents who initially believed they had a typically developing child and then see a regression may experience elevated levels of self-blame, thinking that they did something to cause these newly emerging problems with their child (Neely, Amatea, Echebarria-Doan, & Tanned, 2012). Further, since the diagnosis of ASD is rarely straightforward, the process of identifying and reaching diagnoses for the child's disorder is often unclear and prolonged.

Altiere and Von Kluge (2009) found after a child received a diagnosis of ASD, parents encountered a range of emotions and feelings of sadness, depression, anger, and desperation. When a child is initially diagnosed with ASD, parents often experience intense stress as their child's problems grow more prominent and they struggle to obtain services and treatment for their child (Gray, 2002). The diagnosis of ASD can also bring stressors on the parent and commonly can include increased depression, and marital discord (Weiss & Lunsky, 2011). Lyons et al. (2009) found that the child's autism severity was among the strongest and most consistent predictors of stress across all of the parental stress domains. Increased demands of parenting a child with more severe ASD threatens emotional and relational resources, which can then be associated with more parent and family problems (Lyons et al., 2009).

Unpredictable Course of Autism. When a child is first diagnosed with ASD, parents often experience intense stress as their child's problems grow and they struggle to obtain services and treatment for their child (Gray, 2002). Once a child is diagnosed with ASD, parents begin to acknowledge their child may not live the lifestyle they had envisioned, such as attend college, obtain employment, marry, or have their own children.

Many parents of children with ASD experience a sense of ambiguous loss; the

expectations they once envisioned for their child must change (O'Brien, 2007).

The diagnosis of ASD is often a difficult process. The inherent ambiguity of ASD,

related to the lack of knowledge surrounding its etiology, symptoms, treatment, and

outcome, suggest that parents whose children are diagnosed with ASD experience

conflicting realities and emotions (O'Brien, 2007). The parents' ability to tolerate and

manage the ambiguity of the disability is another source of emotional distress and

confusion. Since ASD presents differently in each child, the specific events that challenge

one child can appear to be handled easily by another. Therefore, the long-term outcome

for individuals with ASD is highly variable, resulting in greater ambiguity (O'Brien,

2007). Furthermore, parents' experiences with a child with ASD point to impairments of

family functioning such as isolating by giving up normal family activities and outings,

lack of spontaneity or flexibility in family life, deficiency of personal social activities,

(Meirsschaut, Roeyers, & Warreyn, 2010). Parents must also deal with the loss of

personal and familial lifestyle they had envisioned before the diagnosis and its impact on

the flexibility of one's schedule.

Reactions of Family and Outsiders. When a child is first born, families typically

establish functional parenting roles and coping styles. However, it is likely that these

styles change significantly upon the discovery of an ASD diagnosis. Not only does the

functioning of the family affect the child, in turn the development of the child also affects

the functioning of the family. When a family is able to draw upon adequate resources and

if the perception of the situation is manageable, then the stress of raising a child with ASD

may never lead to a crisis (Altiere & Von Kluge, 2009a). Parental stress is further

complicated by the fact ASD is not always apparent to outsiders. Externally, children with

ASD often look healthy and 'normal' which can make it difficult for family members and

friends to accept and understand the diagnosis (Ramisch, 2012). Other people in social

settings might also react insensitively to disruptive behaviors because they lack

understanding. Gray's (2002) longitudinal study found that over time the impact of

stigmatization outside of the home declined. However, parents also claimed that it

mattered less to them than it did ten years previously. A contributing factor may be that

several parents noted their success in finding friends who accepted their child's disability

and helped them feel like they led more normal social lives than before.

   Relatives can also be an important source of support but can also be unwilling to

accept the diagnosis. In a study conducted by Hutton and Caron (2005), nearly half of the

grandparents of families studied were not accepting nor understanding of the diagnosis,

with grandfathers being more than twice as likely as grandmothers to not accept the

diagnosis (Hutton & Caron, 2005). Gray (2002) found however, that many parents

reported improved relationships with their extended family, and especially the child's

grandparents, over time. This was in part due to the reality of the child's disability being

confirmed over time and grandparents growing more accepting and knowledgeable of the

situation.

   It is believed that social support is an integral piece of coping with the stress of

having a child with ASD. However, this can be challenging in itself because families may

gradually lose friends because of their limited availability and time (Altiere & Von Kluge,

2009a). Dunn et al. (2001) report failure to receive and seek social support corresponded

with increased levels of spousal problems. Interestingly, Altiere & Von Kluge (2009a)

found that some fathers felt that they lost friends because the friends did not comprehend the struggles associated with raising a child with autism and that others felt that they lost friends due to their inability to spend significant time with them. In contrast, many mothers indicated that their social support came from other mothers they met through support groups and related functions.

Marital Stress. There are conflicting findings on divorce rates for parents with a child with an ASD diagnosis. Higher rates of divorce and separation have been found in parents of children with developmental disabilities in comparison to parents of typically developing children (Risdal & Singer, 2004). Brobst, Clopton & Henrick (2009) report parents of children with disabilities had higher divorce rates than parents without children with disabilities, with a rate of three to six percent higher than the national average. Popular media has reported that parents of children with ASD have higher than average divorce rates (Ramisch, 2012, Sobsey, 2004). Lee (2009) reports parents of younger children with ASD have more varied and a slightly lower average level of marital satisfaction than parents of children without disabilities. Hartley et al. (2012) found that parents of children with ASDs were shown to have a similar risk of divorce as parents of children without disabilities early on, but a higher risk of divorce when the child with ASD reaches adolescence or adulthood.

Having a child diagnosed with ASD can contribute to both positive and negative marital perceptions and stress outcomes (Ramisch, 2012). However, discrepancy exists as parents reported that the developmentally disabled child has brought them closer together (Risdal & Singer, 2004). Sobsey (2004) suggests that extreme marital conflict that often precedes or accompanies divorce can contribute to children's behavior problems making

rise to the question, does the stress of a child with ASD contribute to marital conflict or does the marital conflict contribute to the stress associated with the child's ASD? Hartley, Barker, Baker, Mailick, Seltzer, & Greenberg's (2012) study on marital satisfaction among parents of grown children with ASD found closeness in the mother-child relationship was significantly related to mothers' initial level of marital satisfaction and mothers who reported having a closer relationship with their adolescent or adult son or daughter with ASD also reported a higher level of marital satisfaction. Parents' emotional well-being has been shown to fluctuate along with changes in the symptoms and behaviors of the adolescent or adult child with ASD. Similarly, maternal marital satisfaction is associated with some but not other life circumstances of the grown child with ASD. On average, mothers' marital satisfaction declined across a seven-year study period, which is consistent with parents in the general population (Hartley et al., 2012). These studies suggest a correlation between a positive marital relationship and positive interactions with the child.

The research reporting on marital dysfunction and divorce among families of children with disabilities is inconsistent at best. It is understood that parents of children with ASD do experience higher levels of emotional distress and stress which, ultimately, can affect the marital relationship, but there is very little empirical evidence proving that it contributes to a higher divorce rate. Although there is a risk that a couple may have less time to focus on their marriage when they have a child with a disability, parents are often aware of this challenge and are determined to keep their marriages strong (Brobst, Clopton, & Hendrick, 2009).

Lack of Resources. A diagnosis of ASD places a large and often immediate financial burden on families. Household income may be an important determinant of marital adjustment in parents of children with ASD. Household income has been shown to be a factor in marital satisfaction in the general population; Parents of a child with ASD commonly seek numerous costly services and support that may add to marital stress (Hartley et al., 2012). There is great evidence that early behavioral and therapeutic intervention is critical for improving symptom severity associated with ASD but most intervention strategies are expensive. Many strategies require long hours of interaction with a trained therapist and health insurance often falls short of covering these needs, resulting in parents being expected to pay out of pocket (Sharpe & Baker, 2007). The Autism Society (2014) estimates the lifelong cost of caring for a person with autism ranges from 3.5-5 million dollars. Limited public and private support exists and many programs offered through public education are often inadequate or inappropriate for many children. In addition, the educational programs that are provided are rarely sufficient to address the needs of school-aged children with ASD and are not available to young adults with ASD, leaving most parents seeking out other intervention strategies. The expenses associated with having a child with ASD are not, however, limited to the cost of interventions (Sharpe & Baker, 2007). There are also additional costs associated with extracurricular activities catered to children with special needs, as well as transportation to and from services and respite care (Ramisch, 2012).

Depending on the child's level of needs, one or both parents often must reduce work hours or quit a job altogether in order to care for a child with ASD. Gray (2002) conducted a longitudinal study of families of children with ASD over a ten-year period of

time. He found career problems were among the most common stress factors among parents because of serious limitations for outside employment due to their child's disability. The inability to maintain employment, in turn, affects the financial state of the family, thereby adding to the stress level for parents.

      Support Groups & Other Services. Parents' coping strategies are related to the resources to which they have access. Without these resources, parents are vulnerable and more likely to experience higher levels of stress. Social support is an important moderator of stress for parents of children with ASD, as support can help parents cope by meeting their emotional, practical, and informational needs (Tehee, Honan, & Hevey, 2009). Ramisch (2012) found that higher levels of social support are related to lower levels of anxiety and depression, particularly in mothers.

      Outside services such as support groups, in-home services and respite care also reduced stress among parents. Support groups can serve parents well, as they are able to relate to other parents' struggles with ASD, as well as gaining insight and hope into success stories and accomplishments, which is an important piece of support. Tehee, Honan, & Hevey (2009) found adaptive coping strategies, informal social support and beliefs about the efficacy of the intervention were associated with lower levels of stress. Further, belief in efficacy of the interventions being used pointed to lower levels of pessimism. This was true even in parents of children with more severe presentation of symptoms.

      Behavioral Problems and Impact. Parenting a child with both a developmental disorder and behavior problems can create an especially challenging environment (Brobst, Clopton, & Hendrick, 2009). Research has indicated the behavioral problems of children

with ASD, rather than the severity of the disorder, are associated with elevated

psychological distress in mothers (Lickenbrock, Ekas, & Whitman, 2011 & Rezendes &

Scarpa, 2011). Some problem behaviors include: fascination with particular topics,

people, or objects, perseveration, repetitive behavior, tantrums, repetitive discussion of a

topic, lack of eye contact in communication, misbehavior in public, withdrawal behaviors

and aggressive and violent behaviors (Ramisch, 2012).

The intensity of behavioral issues relating to children with ASD has been shown to

impact parents' stress levels and relationship satisfaction. Mothers whose children have

ASD and reported intense behavior problems reported lower levels of spousal support,

respect for their partners, and commitment to their marriages. Simultaneously, increases in

the behavior problems of the child with ASD may create opportunities for couples to

disagree on parenting strategies (Hartley et al., 2012). Furthermore, parenting stress was

found to be greater when the child's disability was perceived to be more severe and when

the intensity of the child's behavior problems was greater. In addition, stress was greater

for some parents when positive relationship characteristics were lower (Brobst, Clopton,

& Hendrick, 2009).

Changes in Adolescence and Adulthood. Although the diagnosis of ASD usually

occurs in childhood, caring for an individual with ASD is a lifelong endeavor. This care

may place additional stressors on the family and primary caregivers at any stage of the

lifespan (Weiss & Lunsky, 2011). Over the first few years following the diagnosis of ASD

and after obtaining initial services, most families experience a relatively good period of

adjustment. In particular, improvements in the child's sociability, emotional control and

attention span mean that their behavior becomes more orderly and their family's life more settled (Gray, 2002).

The onset of adolescence typically brings more emotional stress and problems worsen with increasing physical and sexual maturity (Tehee, Honan & Hevey, 2009). As the children get older, new behavior problems may arise and old behaviors may persist leaving parents to continually adapt reactions and manage the child's disruptive behaviors (Ramisch, 2012).

Additional obstacles remain into adulthood with the need of living and employment arrangements (Gray, 2002). Parents often become concerned with what will happen once they are no longer able to care for their child and future residential situation becomes more important (Ramisch, 2012). The transition to a different residential setting for a child or adult with ASD, if one is available, requires far more planning and expenses than a typically developed teenager leaving the home for the first time. This transition can evoke a deep sense of loss for the parents (Ramisch, 2012).

Special Education Accommodations

Most students with autism will need some type of special assistance in order to complete their education. The uniqueness (physical, emotional and educational needs) of autism will determine how much assistance one student will require and it will differ from student to student. Students can receive a variety of support services available through special education services in the areas of social, academic, emotional, and/or physical. This type of service will more than likely include special education services in school. For students with disabilities, the right to an adequate education was mandated by Individuals with Disabilities Education Act (IDEA) Amendments of 1997 (Sabbatino & Macrine,

2007) and at no cost to the parents (Bloch, 2014).

All students who receive specialized services in an educational setting have an Individualized Educational Plan (IEP) that outlines personalized educational goals. These services provide educational support to meet students' individualized needs and goals throughout their educational career. According to Claes et al. (2010), "Person-centered planning is a well-known and widely used approach to individual program planning in the field of intellectual and developmental disabilities. Its purpose is to develop collaborative supports focused on community presence, community participation, positive relationships, respect, and competence" (p.432). This individualized planning outlines an array of "procedures and guidelines focused on the creation of fundamental changes in the lives of people with intellectual and developmental disabilities" (Claes, et al., 2010, p. 432).

General Role of the School Social Worker

The roles of the school social workers vary largely from one district to the next and even more so from state to state. Traditionally, school social workers support students in the general population and in the area of special education. School social workers may speak with students and the parents when a child is suspected to need special education services. Often times, social workers are involved in the evaluation of student behavior and mental health concerns. Additionally, school social workers can provide counseling to individual students, facilitate groups, assist families with community resources, consult with teachers, parents and other service providers in the student's life (Weiss, et al., 2013). When school social workers are assisting individual children or groups they may work with students on a variety of issues including behavior problems, emotional issues, peer

relationships, hygiene, anger management, coping skills, grief, substance abuse as well as education and support to families for various resources (How Do Social Workers Help the Families of Children with Disabilities?, 2006).

School Social Worker Role & ASD

The literature that addresses the social workers' roles discuss the position from an ecological perspective including collaboration with a multi-disciplinary team, involvement in the assessment process, supporting and engaging family members, providing support to the school staff and advocating for policy changes (Dababnah et al., 2010). Commonly, school social workers serve as case managers for children with ASD by collaborating with parents, teachers, support staff, school psychologists and other outside support professionals (Comegys & Guggemos, 2014).

Social workers can provide parents with support relating to emotional stress as well as resources to benefit the child with ASD as well as the family. A holistic approach can be utilized by school social workers in supporting the family system. Social workers are able to provide the parents with education about the diagnosis, assessment and treatment options, support processing how the parent feels about the diagnosis and other children, consult with other providers involved for care coordination, as well as collaborate in a plan to assist the child with ASD meet his or her educational goals (Autism Ontario, 2011).

Children with ASD are faced with several challenges in all environments: home, school and community. In addition to direct service with ASD children, school social workers should provide support to other members of the child's ecosystem including

parents, teachers and classmates. Social workers have the ability to assist families with education on ASD, processing family conflicts, negotiation and communication, household changes such as a divorce, separation or loss of a loved one (Autism Ontario, 2011 & Dababnah et al., 2011). VanBergeijk and Shtayermman (2005) recommend school social workers create psycho-educational support groups for parents. Support groups are helpful in supporting the parent in understanding the unique learning needs and communication skills that would be effective with their child as well as support parents in working with the schools to meet their child's needs (VanBergeijk & Shtayermann, 2005). Additionally, school social workers are able to provide parents with community resources that would also benefit stress levels and care planning for their child.

Within the educational setting, social workers are able to support students with ASD on an individual level to discuss peer interactions, stressors relating to educational goals, classroom placement as well as behavior within the school setting (Autism Ontario, 2011). In turn, it is recommended that the school social worker communicate with parents to gain input and perspectives within the educational context that can be utilized to support the ASD child (Autism Ontario, 2011). As children with ASD age and begin to attend school, behavioral problems and stressors from within the home manifest into the school setting (Weiss et al., 2013). Stressors within the home and family life often carry over into the school environment resulting in heightened behaviors, as many students with ASD lack the ability to verbally express feelings (Weiss, Wingsiong & Lunksy, 2013). Additionally Bloch (2014) states since education is currently the most effective intervention available for children with ASD, training for all school staff involved with the child as well all collaboration with parents is essential.

With strong communication between the school social worker and parents, this deficit can be bridged. Collaborative behavior observation in both the classroom and home environment is likely to promote accurate and appropriate evaluations, planning, and programming for the child and family (Bloch, 2014). Therefore, the child can be better understood within the context of what is occurring within the home. Frequently children with ASD are unable to express emotions and others are so impaired they are unable to verbally communicate, resulting in increased behaviors that filter into the classroom.

Minimal research exists on the role of school social workers in supporting parents of a child with ASD or how well social workers are meeting the needs of parents (Weiss et al, 2013). However Autism Ontario (2011) and Doyle & Doyle (2003) point out that parents can benefit from meeting with a social worker by providing individual or counseling services, discussing diagnosis, de-escalation strategies, providing guidance and ongoing support. Therefore, the question remains, what is the role of the school social worker in supporting parents with a child with an ASD diagnosis?

Methods

Research Design

The purpose of this research study is to explore the role of the school social worker in supporting parents with children on the autism spectrum. This research is primarily a quantitative study with qualitative components. Information was gathered via an online survey format via Qualtrics. School social workers were asked to participate by completing an online survey designed by the researcher, which was based on the information gathered from the literature review. Quantitative methods emphasize

objective measurements and numerical analysis of data through collection of a survey, poll or questionnaire (Monette, Sullivan & DeJong, 2011). Quantitative research focuses on collecting numerical data and generalizing it across groups of people (Monette, Sullivan & DeJong, 2011). This research will be used to generalize the school social workers' role in supporting parents with a child with an ASD diagnosis. The information gathered will be used to further understand school social workers' practice in working with parents of a child with ASD and how they view their role and boundaries pertaining to this relationship.

Sample

The population of interest for this research was school social workers who serve students with ASD. The researcher used the Minnesota School Social Workers' Association (MSSWA) as a sampling frame. The research was conducted by contacting MSSWA and gaining approval to contact members. Emails were then sent to members, inviting them to participate in the survey. The goal sample size for this study was 40 participants. However, the survey had 65 respondents participate.

Participants received information outlining the criteria for participation in the survey, an invitation to participate, as well as a link to proceed in taking the survey. The respondents of the survey were required to have had experience working with students with ASD in order to participate. Participants were first asked if they work or have worked as a school social worker serving children with autism spectrum disorders. If not, the survey automatically closed, prohibiting the respondent from answering further questions. This ensured only school social workers serving students with ASD

participated in the survey.

The majority of the respondents were women (95%). The average number of years of experience as a school social worker was 11.5 and a standard deviation of 7.865. The range of experience working with children with an ASD diagnosis was 1-30 years with an average of 10.2 years.

Of the 65 respondents, 60 (92%) were currently working as a school social worker serving children with ASD and 5 (8%) were not. The five respondents who were not school social workers, were not used in the data analysis.

Respondents worked in various settings; this was assessed with a multiple-choice question. Respondents were able to select more than one setting, to account for those who work in more than one educational setting; therefore the results reflect a percentage of over 100%. Of the 60 responses, 13 (22%) work in a pre-K setting, 35 (58%) work in an elementary school, 31 (52%) work in a middle school, 24 (40%) work in a high school, 1 (2%) work in a transitional program and 1 (2%) respondent reported work in "other" and further explained that s/he worked in an "autism treatment facility."

Respondents were asked for the setting in which they worked. This was a multiple-choice question with answers of "rural" "suburban" or "urban." Respondents were allowed to select more than one setting, in the case s/he works in multiple locations. Therefore, the results reflect a percentage of 105. Of the 60 respondents, 30 (50%) reported working in a rural setting, 15 (25%) reported working in a suburban setting and 18 (30%) reported working in an urban setting. The majority of respondents work in rural settings. The majority of school social workers (40.17%) reported working in a general

education setting, with the second highest 21.53% working at a federal setting I. The

setting of the school is defined by the extent of full participation with non-disabled

students in regular classrooms. For example, federal setting I is defined as the student

receives the majority of his/her education in regular education classes, but may be in

special education class no more than 21% of the school day (Arc Guide to Federal

Instructional Settings for Students in Public School, 2012). By law, the federal school

setting is defined on the students' IEP.

Protection of Human Subjects

        All precautions were taken to minimize risks of participation to human subjects in

this research study. Participation in this survey was voluntary throughout the entire

process of this research, as participants had the option to participate in the survey or

decline. This study was reviewed by a research committee and submitted to the St.

Thomas Institutional Review Board. Permission was obtained from the Minnesota School

Social Workers' Association before any members were contacted. Participants received

information explaining their protection and voluntary nature of participation in this

research study. Participants consented to participating by completing the online survey.

        By collecting data electronically through an online survey via Qualtrics, responses

were completely anonymous. There was no known risk or benefit in participating in this

study. The collected data will be stored on a password-protected computer belonging to

the researcher. After completion of the study, the collected data will be destroyed before

July 1, 2015.

Data Collection & Analysis

This study measures the perceptions of school social workers in their role in supporting parents with a child with a diagnosis of Autism Spectrum Disorder (ASD). Quantitative data was obtained through confidential surveys via Qualitrics. An online survey was selected as the method for collecting data due to the potential to reach a large sample population in a fairly short period of time and at a minimal cost to the researcher (Monette, Sullivan & DeJon, 2011). Other benefits of utilizing an online survey is it allows for respondents to remain anonymous, and for the researcher to include both quantitative and qualitative questions (Monette, Sullivan & DeJon, 2011). A disadvantage of using an online survey for this research was there is no opportunity to further investigate information provided by the respondents (Monette, Sullivan, & DeJon, 2011).

The survey was a mix of twenty-one quantitative and qualitative questions, some were closed such as multiple choice or yes/no and others were open-ended. Open-ended questions allowed for the respondent to explain from his or her own perspective. (See Appendix B for complete survey questions.) Quantitative data involves data in the form of numbers and counts, while qualitative data includes words and descriptions (Monette, Sullivan & DeJong, 2011). The qualitative questions required respondents to write their own responses, in their own words. This option allowed for respondents' individual experiences to be recognized within the research (Monette, Sullivan & DeJong, 2011). These responses were then coded into appropriate categories and themes were identified. The survey took respondents approximately fifteen minutes to complete.

The hope is the qualitative questions will reflect the experience of school social workers' role in supporting parents of a child with ASD. The inclusion of qualitative

questions allows the language, perceptions and experiences of respondents to emerge and

allows the researcher to collect information that could have otherwise been missed by

solely using closed-ended questions (Monette, Sullivan & DeJong, 2011).

Validity is the degree to which a measure accurately reflects the meaning of a

variable (Monette, Sullivan & DeJong, 2011). The questions used in the survey relate to

the literature review to ensure content validity. Monette, Sullivan and DeJong (2011)

define face validity as the degree to which a logical relationship exists between a variable

and the proposed measure. Face validity was anticipated to be reached in this research by

having class peers and committee members review the questions. By having the survey

peer reviewed, jargon and errors were eliminated. This also helped to ensure the

questions were reliable, clear to the reader and readers had the same interpretation.

Reliability is defined as the ability of a measure to be consistent (Monette, Sullivan &

DeJong, 2011).

After the data was collected via the Qualtrics survey, this researcher then

completes a descriptive statistical analysis to analyze the results.

Findings

Descriptive Statistics

This study addressed twenty descriptive questions. Of the 65 respondents, 60

(92%) were currently working as a school social worker serving children with ASD and 5

(8%) were not. The five respondents, who were not school social workers, were not used

in the data analysis.

Seventy-two percent of the respondents reported providing 0-10 hours of service to students with ASD in a given week. Nearly all respondents reported providing an average of 0-2 hours per week of support to parents of children with ASD. Furthermore, nine (16%) of the respondents reported providing support to parents on average of "3-5 hours" per week.

The next few questions asked participants about details surrounding parental stress pertaining to having a child with ASD. Respondents were asked "how often parents share details regarding stressors surrounding having a child with ASD?" Eleven out of the 57 respondents (19%) reported "rarely", 29 (51%) reported "occasionally" and 17 (30%) reported "often." None of the respondents reported "never" or "always." The next question asked "how often do parents with a child who has autism report the following stressors: marital status, behavior support, educational needs, negative reactions from family, lack of resources, negative reactions from friends." Fifty-seven of the participants responded (see Figure 1 below). Respondents stated parents reported the areas of behavior support, educational needs and lack of resources as being the three most frequently reported stressors. The least common stressors parents share with school social workers were marital stress, negative reactions from friends and negative reactions from family. (The percentages for each stressor are labeled in the parenthesis in Figure 1 below.) Respondents were also asked if they observed parents of a child with ASD reporting higher levels of stress than parents of children with other disabilities. Respondents were divided in this response, 27 (47%) participants reported "yes" and 30 (53%) reported "no."

		Never	Rarely	Occasionally	Often	Always	Total Responses
	Marital Stress	20 (35%)	21 (37%)	10 (18%)	6 (24%)	0 (0%)	57
	Behavior Support	1 (2%)	4 (7%)	17 (30%)	31 (54)	4 (7%)	57
	Educational Needs	1 (2%)	1 (2%)	18 (32%)	29 (51%)	8 (14%)	57
	Negative Reactions from Family	13 (23%)	24 (42%)	15 (26%)	5 (9%)	0 (0%)	57
	Lack of Resources	7 (12%)	12 (21%)	32 (56%)	5 (9%)	1 (2%)	57
	Negative Reactions from Friends	19 (33%)	21 (37%)	12 (21%)	5 (9%)	0 (0%)	57

Figure 1. Figure shows how often parents with a child who has autism report the above stressors to the school social worker.

The next couple of questions inquired about information pertaining to the role of the school social worker in supporting parents of a child with ASD. All of the respondents believed providing support to parents of a child with ASD should be part of their role of school social worker. Additionally, 84% of participants reported as a school social worker, they should support parents with stressors outside of educational planning pertaining to their child with ASD. It was optional for respondents to explain their answer to this question in narrative form. Twenty-eight (49%) of the respondents chose to explain their answers. Three themes were identified. The majority of the respondents reported school social workers should assist parents with community resources. As one respondent said, *"We should be able to offer support in the form of helping them to find/connect with outside resources for their children and families when necessary."* A second respondent reported *"it is our job to connect them with additional supports outside of the school*

day."

A secondary theme identified was a desire to assist families with various needs and supporting the family as a whole. One respondent wrote *"we are in a unique role as social workers to support families surrounding their child's needs. It is important to look at all aspects within a family that could affect a child's academic, social and behavioral growth. This could include lack of resources, family stress, financial needs, community supports, etc."* A second respondent said, *"I believe we should be looking at the entire family system and offering support where needed."* A third respondent shared the importance of the school and home being connected, *"What happens at home impacts the child at school. Better parent relationships and improve understanding of the student"*

Other respondents felt the social worker should provide minimal support to parents with a child with ASD outside of educational needs. One respondent said, *"I think we need to be a connector between school and community resources, but not become the main support for families."* Another respondent reported lack of time to provide additional support to families, *"Not enough time to do this, refer to outside resources."* An additional *"Social workers can provide resources for community resources, etc. but should not be in a role where they are providing support with parent(s) mental health difficulties, marital difficulties, etc."*

The fifteenth question was nominal and asked respondents "have you, as a school social worker provided support to parents with a child with ASD?" There was a total of fifty-seven responses with fifty-five (96%) of the respondents reporting they had provided support to parents with a child with ASD and 2 (4%) had not.

The next question was ordinal and asked respondents "how often do you, as a

school social worker, provide the following support(s) to parents with a child with ASD?"

The topics addressed eleven areas of stress which included "marital stress, behavior

support skills, referral for community resources, educational goal planning,

psychotherapy, psycho-educational support group, household routines, transition planning,

communication between home and school, individual counseling and family counseling."

Respondents were asked to rate the above categories using the Likert scale of 1=never,

2=rarely, 3=occasionally, 4= often 5=always. Fifty-six of the participants responded to

this question (see Figure 2 below for results, percentages are identified in the parenthesis

below). Support was reported to be given most often in the areas of referral for

community resources, educational goal planning and communication between home and

school. Support was least provided in the areas of psycho-educational support group,

marital stress, family therapy and psychotherapy.

		Never	Rarely	Occasionally	Often	Always
1	Marital Stress	34 (61%)	16 (29%)	4 (7%)	2 (4%)	0 (0%)
2	Behavior Support Skills	1 (2%)	3 (5%)	24 (43%)	23 (41%)	5 (9%)
3	Referral for Community Resources	0 (0%)	3 (5%)	12 (21%)	32 (57%)	9 (16%)
4	Educational Goal Planning	0 (0%)	5 (9%)	13 (23%)	26 (46%)	12 (21%)
5	Psychotherapy	32 (57%)	13 (23%)	6 (11%)	5 (9%)	0 (0%)
6	Psycho-educational Support Group	29 (52%)	11 (19%)	6 (11%)	9 (16%)	1 (2%)
7	Household Routines	6 (11%)	17 (30%)	26 (46%)	7 (13%)	0 (0%)
8	Transitional Planning	10 (18%)	14 (25%)	19 (34%)	12 (21%)	1 (2%)
9	Communication between home and school	0 (0%)	6 (11%)	18 (32%)	21 (38%)	11 (20%)
10	Individual Counseling	26 (46%)	8 (14%)	13 (23%)	9 (21%)	0 (0%)
11	Family Counseling	36 (64%)	11 (20%)	7 (13%)	2 (4%)	0 (0%)

Figure 2. Figure shows how often school social workers provide the above supports to

parents with a child with ASD.

The seventeenth question was qualitative and asked respondents "what supports do

you provide to parents of a child with ASD that seem most beneficial in lowering stress?"

Fifty-two of the respondents answered this question in narrative format. Three themes

arose from the respondents' feedback: resources, emotional support and acting as a liaison

between school and home. The most common responses were referrals to resources as one

respondent stated "*resource and referral for county case management, referral to skills*

worker who come into the home and work with the student and family, and support

through the special education process" to be the most helpful in lowering parental stress.

Another respondent stated *"resource referral, letting them know they are not alone by*

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connecting them with other families." The second most common theme was emotional support, as a respondent reported, *"listening, allowing them to vent and be understood."* A second respondent said *"I think listening to their concerns and normalizing them is very beneficial."*

A third strategy that school social workers found beneficial in lowering parental stress for parents who have a child with ASD was acting as a liaison between the school and home. For example, a respondent shared *"communication between home and school, particularly around classroom homework assignments/routines for students who are in Fed I or II special education programming and are in general education significant portions of their day."* A second respondent stated, *"helping the students' school issues be resolved and for the student to be successful in the school day then sharing strategies with the parents."*

Respondents were asked, "do you believe that a strong relationship between the social worker and the parents of a student with ASD results in better student behavior?" Fifty-five respondents replied with 50 (91%) answering "yes" while 5 (9%) answered "no."

The next question was also nominal and asked respondents, "Do you believe that a strong relationship between the social worker and the parents of a student with ASD results in better academic success?" There were a total of fifty-six responses to this question. Fifty (89%) of the respondents answered "yes" and 6 (11%) answered "no."

The final question asked respondents, "What other support could school social workers provide parents with a child who has ASD to lower familial stressors?" Forty of

the participants answered this question in narrative format. Six out of the forty responded

"unsure." The remaining thirty-four responses were analyzed. Three major themes were

identified: resources, liaison between school and home, and emotional support via parent

support groups. Many of the respondents pointed out the need to provide families with

community resources in efforts to lower familial stressors. As one respondent stated, *"I*

think it would be helpful to provide some psycho-education about autism and information

about how to navigate and access outside resources."

A second theme identified was the need for communication between school and

the home, *"On-going communication, daily logs and reports of behavior and any changes*

in schedule." A second respondent reported the importance of *"Regular communication*

about successes at school, regular opportunities for parents to ask questions."

The last theme identified was a desire to provide support groups for parents within

the school. This is demonstrated by one respondent's feedback, *"a parent support group*

facilitated through the school."

Discussion

This study focused on the school social workers' role in supporting parents with a

child who has autism spectrum disorder. As Newsome (2000) reported, there is a deficit in

research pertaining to this topic. What is known, however, is parents of a child with ASD,

frequently experience intense stress as their child's symptoms grow and also struggle to

obtain services and treatment for their child (Gray, 2002). Furthermore, parents with a

child who has ASD, experience higher levels of marital stress and financial constraints in

obtaining resources (Altiere & Von Kluge, 2009; Borbst, Clopton & Henrick, 2009; Gray,

2002; Hartley et al., 2012; Hutton & Caron, 2005; Lyons et al., 2009; Meirsschaut, Roeyers & Warrren, 2010; Neely, Amatea, Echebarria-Doan & Tanned, 2012; O'Brien, 2007; Ramisch, 2012; Risdale & Singer, 2004; Sobsey, 2004; Weiss & Lunsky, 2011).

School social workers are supporting students and their families more frequently, as diagnosis of ASD has increased drastically over the past decade. In fact, children are being diagnosed with ASD at a growth rate of 1.148% each year, which is the fastest growing rate of any developmental disability (Autism Society, 2014). Ninety-six percent of the participants reported providing support to parents of a child with ASD. With an expanding number of people with autism, school staffs are in turn faced with difficult behaviors and must work closely with the student and their family to foster a positive educational experience (Doyle, D. & Doyle, E., 2003). Therefore, the question is, what is the school social workers role in supporting parents of a child with ASD?

Weiss, Wingsiong & Lunksy (2013) explain stressors within the home and family life often carry over into the school environment resulting in heightened behaviors, as many students with ASD lack the ability to verbally express feelings. How much support should school social workers provide to parents? Additionally what supports are being provided by school social workers and which are not?

 Ninety-three percent of the respondents reported spending up to twenty hours of service to students with ASD in a given week. This finding indicates virtually all school social workers are providing support to students with ASD, therefore, there is a need for a greater understanding of the school social workers' role in working with those students and their families. The majority of school social workers reported providing an average of 0-2 hours of service and support to parents of a child with autism in a given work week. A

large percentage of the respondents reported parents "occasionally" and "often" share details regarding stressors surrounding having a child with ASD.

Respondents reported parents most commonly report stress in the areas of behavior support, educational needs and lack of resources. This is consistent with previous literature; as children with ASD begin formal education, it is common for behavioral problems and stressors from within the home manifest into the school setting (Weiss et al., 2013). The intensity of behavioral concerns pertaining to children with ASD has been shown to impact parents' stress levels and relationship satisfaction. Mothers of children with ASD reported intense behavior problems, lower levels of spousal support, respect for their partners, and commitment to their marriages. Furthermore, the behaviors simultaneously increase opportunities for couples to disagree on parenting strategies (Hartley et al., 2012).

The school social worker should communicate with parents to gain input and perspectives within the educational setting, which in turn can be used to support the child (Autism Ontario, 2011). Bloch (2014) explains since education is currently the most effective intervention available for children with ASD, training for all school staff involved with the child as well as collaboration with parents is essential.

 Stress related to marital conflict and negative reactions from friends and family were less often reported to school social workers. According to Ramisch (2012) at times it is difficult for friends and family members to accept and understand the ASD diagnosis because the child looks "normal" from the outside leaving parents feeling unsupported. Hutton and Caron (2005) found nearly half of the grandparents of children with ASD were

neither accepting nor understanding of the diagnosis. Therefore, this issue is likely occurring, however parents are not reporting it to school social workers.

All of the respondents reported providing support to parents with a child with ASD should be part of their role in being a school social worker. A majority of the school social workers believed they should provide support to parents with stressors outside of educational planning with the most common areas being connecting parents to community resources, a desire to provide emotional support to the family, and lastly act as a liaison between the school and home. A small number of school social workers reported their role should entail minimal support to parents outside of educational needs.

In this study, school social workers most commonly reported providing support to parents in the areas of referral for community resources, educational goal planning and communication between home and school. Support was least provided in the areas of psycho-educational support group, marital stress, family therapy and psychotherapy. This is consistent with Weiss, et al. definition of the school social worker role as inclusive to assisting families with community resources and consulting with parents (2013). Another source described the role of the social worker as providing support in identifying resources and providing education to families (How Do Social Workers Help the Families of Children with Disabilities?, 2006).

School social workers reported providing resources, emotional support and acting as a liaison between the home and the school to be most beneficial in lowering parental stress. Ninety-one percent of the school social workers believe when a strong relationship between the school and parents of a student with ASD results in improved student behavior. In addition, 89% of the respondents believe when a strong relationship exists

between the social worker and the parents of a student with ASD, better academic success results.

The three main supports school social workers provide to parents in efforts to lower familial stress include: resources, acting as a liaison between the school and home, and emotional support via parent support groups.

When respondents were asked "what other support could school social workers provide parents with a child who has ASD to lower familial stressors," three themes emerged: resources, liaison between school and home, and emotional support via parent support groups. These findings mirrored many of the same supports that school social workers reported already using as interventions. This fits with Bloch's (2014) report that collaborating efforts between the classroom and home were likely to promote effective evaluations, planning and programming for the child and family. Therefore, the child can be better understood within the context of what is occurring within the home. Frequently children with ASD are unable to express emotions and others are so impaired they are unable to verbally communicate, resulting in increased behaviors that filter into the classroom.

Additionally, groups can be of great support for parents as they provide opportunities to relate to other parents' experiences, while instilling hope through hearing success stories. Hope is a vital piece of support. Groups provide parents with strategies to use in coping with the additional stressors. Tehee, Honan, & Hevey (2009) found adaptive coping strategies, informal social support, and beliefs about the efficacy of the intervention were associated with lower levels of stress.

Implications

Practice. The findings from this study provide implications for clinical social workers in practice. School social workers need to be aware of the stresses parents of a child with ASD experience and how these impact the family. Allowing parents to discuss their feelings and frustrations is essential. Stressors within the home and family life often carry over into the school environment resulting in heightened behaviors for students with ASD (Weiss, Wingsiong & Lunksy, 2013).

The participants in this study reported providing various supports to parents who have a child with ASD. There were differing perspectives on what those supports should be. Of those who responded, supports were reported most often in the areas of referral for community resources, educational goal planning, and communication between home and school. Support was least provided in the areas of psycho-educational support group, marital stress, family therapy and psychotherapy. Respondents felt it is important to provide parents with community resources, provide ample communication between the schools and home and lastly showed a desire to support parents' emotional needs via parental support groups. Support groups were not frequently reported as a tool for support in the school social workers role; however many respondents felt it would an area of support that is needed.

By examining the role of the school social worker and identifying which supports and practices are within the realm of this position, a base line can be established to create the best practices in this setting.

Policy. There are many implications that arose from this research. First, I believe

school social workers can provide great support to parents of children with ASD. Schools generally do not bill insurance companies for services. However, if billing were possible it may afford additional support to families, specifically parents of a child with ASD. These supports could include support groups, family therapy; more time allocated for discussion on school/home interventions as well as discussion about community resources. Previous research has indicated support groups can be of great benefit to parents. Groups provide an opportunity to relate to other parents' struggles with ASD, as well as gaining insight and hope from hearing success stories, which is an important piece of support. Tehee, Honan, & Hevey (2009) report coping strategies, social support and beliefs about the efficacy of the intervention were associated with lower levels of stress.

Research. This study implies that further research is needed in order to gain more understanding of best practices school social workers should use in supporting parents of a child with ASD. Parents of children with ASD face many additional stressors that parents of a normally developing child generally do not. Research reveals social support serves as an important mediator of stress for parents of children with ASD. Support can help parents cope by meeting emotional, practical, and informational needs (Tehee, Honan, & Hevey, 2009). Ramisch (2012) found higher levels of social support result in lower levels of anxiety and depression, specifically amongst mothers.

As described in this study and previous literature, it is clear that parents of a child with ASD experience various stressors. School social workers have the training and ability to provide supports. However, it is not clear what the role of the school social worker should be. What is known is the closer the relationship is with the school and parents of the student with ASD, the better the behavior and academic outcomes are for the student.

Limitations

There are limitations to the present study. The study had a relatively small sample size of sixty-five respondents, which limits the ability to generalize the findings. This research targeted a highly specific population of professionals and, thus, further limited the overall ability to generalize the results for this research, as the research is limited to members of the Minnesota School Social Workers' Association. The study gathered information via an Internet survey, therefore there is the possibility the participants misinterpreted content. Additionally, participants may not have answered questions honestly or accurately. There is no way for the researcher to ensure all of the participants are indeed school social workers serving students with autism.

Conclusion

The purpose of this study was to determine what supports school social workers are providing to parents of a child with autism and to determine what the school social workers' role is in this relationship. The supports school social workers are providing to parents of a child with ASD are varied. The three most common supports were referrals for community resources, emotional support and acting as a liaison between school and home.

This study provided the reader with information about school social workers' experiences in supporting parents of a child with ASD. The study intended to identify the school social workers perspectives on the stressors that parents are experiencing in relation to having a child with ASD as well as determine what supports were being utilized by school social workers. The survey results identified mixed responses of a

variety of tools school social workers are using. All respondents believed it was their responsibility as the school social worker to provide support to parents of a child with ASD. The majority of participants reported providing support through referrals to community resources, acting as a liaison between school and the home, and providing emotional support.

This research serves as a reminder to social workers that even though the child has the diagnosis and is the primary client, parents are also greatly impacted and need to be supported and heard. By providing parents with various supports (resources, psycho-education, support groups, etc.), the intent is to lower stress and support the family as a whole.

Since school social workers reported providing resources, emotional support and acting as a liaison between the home and the school to be most beneficial in lowering parental stress, more of these services should be part of the role of school social worker. Nearly all respondents reported that a strong relationship between the school and parents of a student with ASD results in improved student behavior. Furthermore, 89% of the respondents believe when a strong relationship exists between the social worker and the parents of a student with ASD, better academic success results. Since both student behavior and academics are impacted positively by a strong relationship between school and parents, the school social worker role should focus on this aspect for the betterment of the student and their family.

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Diagnostic Criteria for 299.00 Autistic Disorder

A. A total of six (or more) items from (1), (2), and (3), with at least two from (1), and one each from (2) and (3):

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

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

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

> (a) 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)
>
> (b) in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others
>
> (c) stereotyped and repetitive use of language or idiosyncratic language
>
> (d) lack of varied, spontaneous make-believe play or social imitative play appropriate to developmental level

3) restricted repetitive and stereotyped patterns of behavior, interests, and activities as manifested by at least one of the following:

> (a) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus
>
> (b) apparently inflexible adherence to specific, nonfunctional routines or rituals
>
> (c) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)
>
> (d) persistent preoccupation with parts of objects

- Delays or abnormal functioning in at least one of the following areas, with onset prior to age 3 years: (1) social interaction, (2) language as used in social communication, or (3) symbolic or imaginative play.

- The disturbance is not better accounted for Rhett's Disorder or Childhood Disintegrative Disorder

Diagnostic criteria for 299.80 Asperger's Disorder

A.   Qualitative impairment in social interaction, as manifested by at least two of the following: (1) marked impairment in the use of multiple nonverbal behaviors such as eye-to- eye-gaze, facial expression, body postures, and gestures to regulate social interaction (2) failure to develop peer relationships appropriate to developmental level (3) a lack of spontaneous seeking to share enjoyment, interests, or achievements with other people (e.g., by lack of showing, bringing, or pointing out objects of interest) (4) lack of social or emotional reciprocity

B.   Restricted repetitive and stereotyped patterns of behavior, interests, and activities, as manifested by at least one of the following:

.   (1) encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus

.   (2) apparently inflexible adherence to specific, nonfunctional routines or rituals

.   (3) stereotyped and repetitive motor mannerisms (e.g., hand or finger flapping or twisting, or complex whole-body movements)

.   (4) persistent preoccupation with parts of objects

C.   The disturbance causes clinically significant impairment in social, occupational, or other important areas of functioning.

D.   There is no clinically significant general delay in language (e.g., single words used by age 2 years, communicative phrases used by age 3 years).

E.   There is no clinically significant delay in cognitive development or in the development of age-appropriate self-help skills, adaptive behavior (other than in social interaction), and curiosity about the environment in childhood.

F.   Criteria are not for another specific Pervasive Developmental Disorder or Schizophrenia.

299.80 Pervasive Developmental Disorder Not Otherwise Specified (Including Atypical Autism)

This category should be used when there is severe and pervasive impairment in the development of reciprocal social interaction associated with impairment in either verbal or nonverbal communication skills or with the presence of stereotyped behavior, interests, and activities, but the criteria are not met for a specific Pervasive Developmental Disorder, Schizophrenia, Schizotypal Personality Disorder, or Avoidant Personality Disorder. For example, this category includes "atypical autism"—presentations that do not meet criteria for Autistic Disorder because of late age at onset, atypical symptomatology, or sub threshold symptomatology, or all of these.

Survey Guide
Primary Question: What is the school social workers' role in supporting parents of a
child who has Autism Spectrum Disorder (ASD)?

Demographic Questions

1. Do you currently work as a school social worker serving children with Autism
   Spectrum Disorders (ASD)?   Yes or No

2. Do you work in the following settings:
   Pre-K   Yes or No

   Elementary   Yes or No

   Middle School   Yes or No

   High School   Yes or No

   Transitional Program   Yes or No

3. Is the school(s) you work in located in a rural, suburban or urban environment?

4. What percentage of your time do you spend working in the following settings:
   General Education _____

   Federal Setting I _____

   Federal Setting II _____

   Federal Setting III _____

   Federal Setting IV _____

   Federal Setting V _____

   Federal Setting VI _____

   Federal Setting VII _____

   Federal Setting VIII _____

5. How many years have you been a school social worker?

6. How many school years have you served students with ASD?

7. On average, how many hours of direct service do you provide to students with ASD in a given week?

   0-10 hours

   11-20 hours

   21-30 hours

   31+ hours

8. On average, how many hours of service/support per week do you provide to parents of
   children with autism?

   0-2 hours

   3-5 hours

   6-9 hours

   10+ hours

9. Your gender: Male, Female or Transgender

Parental Stress

10. On a scale of 0-5, how often would you estimate parents share with you details regarding stressors surrounding having a child with ASD? (1=never, 2=rarely, 3=occasionally,   4= often 5=always):

    1   2   3   4   5

11. On a scale of 0-5 how often do parents with a child who has autism report the following stressors to you as the school social worker (1=never, 2=rarely, 3=occasionally, 4= often 5=always):

Marital Stress   1   2   3   4   5

Behavior support   1   2   3   4   5

Lack of Resources   1   2   3   4   5

Educational Needs   1   2   3   4   5

Negative Reactions from Family

                                   1   2   3   4   5

Negative Reactions from Friends

                                   1   2   3   4   5

12. In general, would you say parents with a child with ASD report higher levels of stress than parents of children with other disabilities?

    Yes or No

Role of the Social Worker in supporting parents with a child with ASD

13. Do you believe providing support to parents with a child with ASD should be part of your role as a school social worker?

14. Do you believe a school social worker should support parents with stressors outside of educational planning pertaining to their child with ASD?

    Yes or No, Please explain.

15. Have you, as a school social worker provided support to parents with a child with ASD?

    Yes or No

16. How often do you, as a school social worker, provide the following support(s) to parents with a child with ASD? (1=never, 2=rarely, 3=occasionally, 4= often 5=always):

Marital Stress	1	2	3	4	5
Behavior Support Skills	1	2	3	4	5
Referral for Community Resources	1	2	3	4	5
Educational Goal Planning	1	2	3	4	5
Psychotherapy	1	2	3	4	5
Psycho-educational Support Group	1	2	3	4	5
Household Routines	1	2	3	4	5
Transitional Planning	1	2	3	4	5
Communication between Home and School					
	1	2	3	4	5
Individual Counseling	1	2	3	4	5
Family Counseling	1	2	3	4	5

17. What supports do you provide to parents of a child with ASD that seem most beneficial in lowering stress?

18. Do you believe that a strong relationship between the social worker and the parents of a student with ASD results in better student behavior?

    Yes or No

19. Do you believe that a strong relationship between the social worker and the parents of a student with ASD results in better academic success?

    Yes or No

20. What is the most common support(s) you provide to a parent(s) of a child who has ASD?

21. What other support could school social workers provide parents with a child who has ASD to lower familial stressors?