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# Perspectives on Living Situations for Children with Classic Autism

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Perspectives on Living Situations for Children with Classic Autism

By Meghan Constantini

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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**

The purpose of this qualitative study was to interview parents of children with severe autism and professionals work in residential settings to understand their perspectives of living situations for children with severe autism. Challenging behaviors occur with more frequency and intensity in children with severe autism. Living situations have been shown to have a negative impact on behaviors and the quality of life of a child with autism, as a typical home setting can be over stimulating and overwhelming to children with autism due to the nature of their diagnosis. (Nasir & Tahir, 2012). Findings from previous research show that children with autism have individualized needs and thrive in settings that are designed to meet the unique needs of autism (Feinberg & Vacca, 2000). This study found that challenging behaviors in autism increase parental stress and that more public awareness is needed. Additionally, ideal living situations and suggestions for social workers who work with families impacted by autism were described.

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## Introduction

Many individuals, families and communities are affected by autism. Autism was first identified in the 1940s, but over the past few decades the prevalence of autism has skyrocketed. According to the Centers for Disease Control and Prevention (CDC), approximately one in 88 children have autism which occurs in all racial, ethnic, and socioeconomic groups in the United States (2012). Widespread awareness of the prevalence of autism has prompted an increase in research. However, the growing needs of people with autism have surpassed the capacity to properly fund clinical research on effective treatment options, including living arrangements, for people with autism (CDC, 2012; Dawson, 2012).

It is reported that a lifetime of care for a person with autism is \$3.2 million (CDC, 2012). These staggering statistics can overwhelm a parent who is raising a child with classic autism, referred to as “autism,” or “severe autism” in the present study, which falls on the most severe end of the spectrum (CDC, 2012). Families can become emotionally and physically consumed with the challenges presented by having a child who falls on the severe end of the spectrum of autism (Bennison, 2012). Because of these challenges, some families make the painful decision to move their child out of the family home and into a residential setting. Though this choice is controversial, children with autism and their families can benefit from living situations that are designed with the intention of promoting quality of life by reducing challenging behaviors for people with autism (Brand, 2011; Corman, 2009).

Many studies have examined living situations for people with autism (Felce, Perry, Lowe & Jones, 2011; Gerber, Bessero, Robbiani, Courvoisier, Baud, Traoré, & Galli Carminati, 2011; Van Bourgondien, Reichle, & Schopler, 2003). Studies show that when a child with autism lives in a setting that that improves their quality of life by addressing unique sensory, emotional, and

physical needs, they tend to require fewer behavioral interventions. This can result in less costly treatments and an improved quality of life for families of people with autism (Brand, 2011; Feinberg & Vacca, 2000).

The role of a social worker is vital to a parent raising a child with severe autism, especially when concerns regarding barriers or opportunities to quality living situations arise (Autism Speaks, 2011). Social workers are positioned to learn from families impacted by autism and inform policy makers to make legislative decisions which can have a positive impact on improving living situations for children with autism (Feinberg & Vacca, 2000; Gitterman & Germaine, 1976). Living situations for people with autism must be addressed across the lifespan, but for the purpose of this paper children under the age of 18 in Minnesota will be the focus. The present study will examine perspectives of residential situations for children with severe autism. It will explore previous research on quality of life issues for people with autism and their families, as well as the impact that a living situation can have on people with autism.

A review of previous studies on autism and the impact that residential settings can have on individual and family affected by autism will tie into the present qualitative study of a social work student's one-on-one interviews with parents of children with autism and professionals who support children with autism. The interviewee's perspectives of living situations for children with autism will be explored to understand dynamics of the barriers and opportunities of the residential needs that children with autism have to improve quality of life, as well as the perceived role of social workers.

A conceptual frame work made up of personal experience, a family systems lens, and an ecological theoretical perspective will be applied to the present study and methodology of research will be described. The purpose of the present study is to examine the perspectives of

parents and professionals on living situations, in the family home or in residential settings, for children with severe autism The role parents and professionals feel social workers can play in providing support to increase quality of life for children with autism and their families with also be examined.



### **Definition of Terms Used in Present Study**

***Autism:*** Autism can be broadly defined as a developmental disability that affects brain activity causing social, communication, and behavioral challenges that fall across a spectrum of severity. Classic autism, referred to simply as “autism” in the present study, is the most severe form of autism that causes significant impairments which lead to an increase of challenging behaviors (American Psychiatric Association, 2000; CDC, 2012).

***Family Home:*** For the present study, “family home” will refer to the setting where a family-of-origin with a child with autism resides.

***Living Situation:*** For the present study, “living situation” will broadly refer to where a child with autism lives, either in a family home or in a residential setting.

***Quality of Life:*** The definition of quality of life has vast variations. For the purpose of the present study we will refer to quality of life as having “validity and purpose in giving a historically socially and unvalued group a voice in how services are delivered and experienced,” which emphasizes “human experience and factors related to well-being” (Plimley, p. 206, 2007).

***Residential Setting (RS):*** For the present study, any setting (e.g. group home, campus institution, etc.) that a child with autism resides which is not in the family home will be referred to as a “residential setting,” unless otherwise noted.

### **Literature Review**

Research dedicated to the topic of autism is vast. Previous research has shown how autism varies by individual and examines the challenges families face when raising a child who has autism (Gerber et al., 2011; Plimley, 2007). Providing options for resources and support can have an impact on quality of life for people with autism and their families (Dabrowska, 2010; Downie, 2008). Though autism has more recently been widely researched from many perspectives and in many capacities (Gerber et al., 2011), there seems to be a gap in research as fewer studies are available on the impact that the type of living situation has on children with autism (Hubel, Hagell & Sivberg, 2008).

There is urgency in supporting children and families who are severely impacted by autism because of the stress that severe autism can cause for those who have it and the families who care for them (Ramisch, Timm, Hock, & Topor, 2013). In the present study, an overview of autism will be discussed and the following themes will be explored: the challenges that families of children with autism endure, past and current living situations for children with autism, living situations as a means to improve quality of life, efforts to improve living situations for children with autism, and the role of social workers who serve children with autism and their families.

### **Overview of Autism**

Autism is a developmental disorder which includes symptoms of significant language delays, social and communication challenges, and distress caused by sensory overload. Autism is not detectable by medical or blood tests. Clinicians diagnose autism in many ways, including by observing the child's behavior (CDC, 2012). The cause of autism remains unknown and the debate continues as to why this population continues to grow (Volk, Hertz-Picciotto, Delwiche, Lurmann, & McConnell, 2011). Research dedicated to the topic of autism can be contradictory,

however one thing which is certain is that children with autism and their families need ever-increasing emotional, physical, and financial support to thrive as the rate of diagnosis continues to grow (Bennison, 2012; Krauss, Seltzer & Jacobson, 2005). According to a parent, “Autism is a heartbreaking disorder... we simply cannot manage alone” (Beals, 2003).

### **Challenging Behaviors: Repetitive Behaviors and Sensory Issues**

Repetitive behaviors are typical of a child with autism and have been shown to have a negative effect on family life, learning, and in opportunities to socialize (Johnson & Hastings, 2001). Examples of repetitive behaviors include rhythmic rocking, arm flapping, object spinning, hand staring, eye rolling, and other acts of self-stimulating behaviors (Levinson & Reid, 1993). The patterns of repetitive behaviors can take over a child’s life when their autism is severe as these behaviors can deteriorate mood and increase challenging behaviors, thus causing increased stress and a multitude of obstacles for children with autism and their families (Boyd, McDonough, Rupp, Khan, & Bodfish, 2011).

Children with autism have unique sensory abnormalities that have been shown to be a contributing factor to an increase of challenging behaviors (Blairs, Slater, & Hare, 2007; Gerber et al., 2011). Examples of sensory issues include an imbalance between being hyper and hyposensitive to stimulation, sensory overload involving sight, sounds, smell, taste, and/or touch, and sensory processing distortions (Harrison & Hare, 2004). Simply running a vacuum can cause a child to lose control of themselves due to intense sensory overload. However, children with severe autism react differently to sensory stimulation, making hard to predict what a child’s trigger is that may cause them to panic. The spectrum of autism is broad, and the more severe a person’s autism is the more severe their challenging behaviors can be (Felce, Perry, Lowe & Jones, 2011; Reese, Sherman & Sheldon, 1998).

### **Challenging Behaviors: Aggressive and Self-Injuring Behaviors**

Aggression (e.g. hitting, kicking, biting, or destruction of property) and self-injuring (head-banging, hair-pulling, or consuming non-food or toxic items) behaviors are displayed by many children with severe autism (Hodgetts, Nicholas, & Zwaigenbaum, 2013; Ramisch et al., 2013). Aggression and self-injuring behaviors are a delicate issue for families to discuss. Because of this, children with autism and their families may become isolated from their community and society as a whole (Mike Anson, personal communication, December 2012). An intervention that many families face as a last resort is to move their child who is severely autistic and has severely aggressive, self-injuring into a residential setting, yet sadly these challenging behaviors can also be a reason for not being accepted into residential treatment programs (Hodgetts, Nicholas, & Zwaigenbaum, 2013; Krauss, Seltzer & Jacobson, 2005).

There are no proven medications or behavior treatments that have been shown to cure autism or eliminate sensory issues, repetitiveness, aggressiveness, self-injuring and other challenging behaviors displayed by a significant number of children who have the most severe symptoms of autism. Many children who have autism that show extreme challenging behaviors are tranquilized or physically restrained after a behavior has occurred, as opposed to targeting prevention (Blairs, Slater, & Hare, 2007; Hodgetts, Nicholas, & Zwaigenbaum, 2013). Because there are no known pharmacological treatments to treat mood and behavior issues in children who are severely impacted by autism, the stress levels increase dramatically for these individuals and their families. (Boyd, McDonough, Rupp, Khan, & Bodfish, 2011; CDC, 2012).

### **Families of Children with Autism**

The experiences of families who have a child with autism living in the family home or in a residential setting are important to understand as the levels of stress for raising a child who has

autism has been shown to be higher for parents than any other disability (Mancil, Boyd, & Bedesem, 2009; Dabrowska & Pisula, 2010). Gaining more concrete knowledge of what life is like for children with autism who have challenging behaviors can improve quality of life for people with autism and their families. Sharing personal stories with wider audiences (e.g. social workers, tax payers, and policy makers) offers a glimpse into the life of a family who struggles to care for their child with autism with the hopes of gaining more attention to receive increased support and services (Newsome, 2000).

### **Raising Awareness: Stress Endured by Families of Children of Autism**

Though families tend to be resilient, the mounting chronic pressures of raising a child with autism can compromise physical and mental health, all while draining the family's resources (Bennison, 2012). One study reported that couples who have a child with autism are more likely to end divorce than couples of children with other types of disabilities (Newsome, 2000). Research which measured the types of stress that parents endure and coping strategies utilized found that parents who are more supported when raising their child with autism feel less stress and burden (Pottie and Ingram, 2008). Unfortunately, when a child displays aggressive and other dangerous challenging behaviors as a result of having autism, their access to services including treatment, learning opportunities, and other daily activities becomes very limited, thus increasing stress, negatively impacting interpersonal relationships, and decreasing hope for their family members (Hodgetts, Nicholas, & Zwaigenbaum, 2013).

Parents encounter endless challenges when raising a child with autism. Processing grief, caring for siblings, navigating complex insurance plans or paying for services out of pocket, and juggling therapy appointment are just a few obstacles that families must overcome (Bennison,

2012). Raising awareness about the stress endured by families of children with autism can lead towards improved outcomes for children with autism and their families (Autism Speaks, 2011). According to AutismOne, a world-wide platform to educate, advocate, and fundraise for autism, “Parents are the driving force of the autism community because the issues are too sacred and the stakes too high to delegate to outside interests” (Hickman, 2006). Describing hardships to people who have never interacted with somebody who has severe autism helps explain why additional supports and services, including increased access to quality living situations, are needed for children with autism and their families (Corman, 2009; Downie, 2008).

### **Economic Impact of Raising a Child with Autism**

The economic impact on families of raising children with autism who have challenging behaviors is deep, as it is estimated that behavioral and educational treatment interventions can cost an average of “\$40,000 to \$60,000 per child per year” (CDC, 2012). Studies show that a lack of funding for early interventions can lead towards more costly interventions as more severe challenging and aggressive behaviors emerge (Downie, 2008). Aggressive behaviors can negatively impact the well-being of family members, which has a domino-effect of increasing cost of care for physical and mental health for loved ones of children with autism (Hodgetts, Nicholas & Zwaigenbaum, 2013). Increasing supportive living options that are equipped to reduce or perhaps even prevent challenging behaviors for children with autism can greatly decrease the emotional and financial costs accrued by their families and taxpayers (Autism Speaks, 2008).

### **Living Situations for Children with Autism**

The present study will focus on living situations in Minnesota to narrow the demographics and to focus on the needs of children with autism in Minnesota. The types of

residential living situations available to children with autism vary from state-to-state in the United States. In Minnesota, families find it “difficult or impossible to access appropriate residential services” for their children with severe autism. “Often, these families end up in one crisis situation after another and their children move from one unstable placement to another; they even sometimes end up in programs outside Minnesota, far from home.” Clearly, Minnesota is struggling to offer quality living situations for children with severe autism (Minnesota Department of Human Services, 2013).

### **Brief History of Living Situations for Children with Autism**

From institutions, to deinstitutionalization in the 1970’s, to family and group homes and other types of residential settings, the disability rights movement has played a key role in abolishing inhumane institutional settings for people with all types of disabilities and creating new and innovative ways for people with disabilities, including autism, to live with greater independence. Establishing the Americans with Disabilities Act, which legalizes equal opportunities for people with disabilities, brought people with disabilities “out of the shadows... without pity” (Shapiro, 1994). Because of these efforts, people with disabilities have more access to services and for many, an improved quality of life.

For most, the end of a long era of dismal institutions was a victory. To some, the closing of institutions was harmful because children who are so severely impacted by autism thrive in an “institutional-like” setting. Not the appalling institutions of the past which violated basic human rights, but a new type of institution that caters to the unique needs of children with severe autism. The “least restrictive environment” was coined as a way to integrate people with disabilities into the community during the Olmstead hearings (U.S. Department of Health and Human Services, n.d.). Though it can be tough to explain to those who fought hard to deinstitutionalize the system

and create a least restrictive environment, some children with autism do not thrive unless they live in a more structured and rigid environment. (Mike Anson, personal communication, December 2012).

The typical four-person group home setting that works for so many with other types of disabilities has the same sensory and structural restrictions that a typical family home has for children with autism. In 2009, a group of parents in Minnesota who all have children with autism came to together to form the End of the Spectrum, a non-profit organization whose purpose is “to serve individuals with severe autism by developing replicable campus housing models that meet the sensory needs of this population while emphasizing a healthy milieu.” Stakeholders with the End of the Spectrum are working to “increase public and professional awareness of the need for appropriate out-of-home placement options, including changing legislation where necessary.” These families, who are deeply impacted by the challenges of raising a child with autism, have recently proposed an approach of campus-style living for their children in Minnesota (End of the Spectrum, 2013).

### **Living Situations as a Means to Improve Quality of Life**

The present researcher’s personal experience has shown that children with autism have beautiful personalities and many great attributes that are often masked by an environment that is overwhelming to their senses. The question of where children with autism should live is debated by families and professionals alike; though it seems to be in a child and family’s best interest for a child to remain in the home, the reality is that some children with autism are so severely impaired by challenging behaviors that an out-of-home placement is ultimately the best choice (Minnesota Department of Human Services, 2013).



A family home or residential setting can impair a child's behavior by over stimulating their senses (Ackley, Fields & Skinner, 2013). By modifying environments that address the suspected causes (e.g. transitions, absence of preferred activities, and fear-provoking stimuli), challenging and aggressive behaviors can be greatly reduced or even eliminated. Additionally, environmental interventions that are based upon assessments of evidence-based practices that indentify the specific needs unique to each individual with autism can lead towards greater outcomes of effective care, thus increasing the quality of life for a child with autism (Cale, Carr, Blakeley-Smith, & Owen-DeSchryver, 2009).

### **One Size Does Not Fit All**

Each child who has autism is unique. The impact that a living situation has on a child with autism can vary greatly as the spectrum of severity of autism is broad. Where we live affects our quality of life, and this is especially true for children with autism. The best type of a living situation for children with autism is one that reduces challenging behaviors and improves quality of life for children with autism, their family, and their community (Siaperas & Beadle-Brown, 2006). The quality of the living situation and how it is equipped to meet the many needs of autism varies from child-to-child, and also varies by each home or residential setting, which is important to consider when describing what a quality living situation looks like (Feinberg & Vacca, 2000).

A child's quality of life can improve if their environment it catered to meet their needs. One study reports that "individualizing a person with autism's daily schedule and providing choices increases meaningful participation in daily activities and reduces challenging behaviors." In other words, for children with autism, one size does not fit all when considering living situations. Examining individual perspectives of what ideal living situations are for children who

have severe autism is an essential component of increasing the quality of living situations (Hodgetts, Nicholas, & Zwaigenbaum, 2013; Van Bourgondien, Reichle, & Schopler, 2003).

### **The Family Home vs. a Residential Setting**

Due to the complexities of symptoms, it is often times easier for a child with severe autism to live in an environment that is designed to support people with autism. Often times, the more severe the negative behaviors of a child with autism are, the more likely their family is to make the decision to move the child into a residential setting (Corman, 2009). Residential settings that address the unique needs of children with autism can teach new skills, increase independence, offer increased structure and programs, and reduce stress for families (Krauss, Seltzer & Jacobson, 2005).

### **Effective Interventions in Residential Settings that Reduce Challenging Behaviors**

Previous research supports the notion that a residential setting and quality of life issues are positively connected. Residential setting plays a key role in a person's quality of life. In settings created with the individualized needs of autism in mind, the residents showed "higher levels of confidence and independence and fewer accounts of challenging or complex behavior" (Brand, 2011).

Often times, simple interventions can reduce or eliminate challenging behaviors. For example, rigorous exercise has been shown to be effective in reducing negative behaviors (Levinson & Reid, 1993). Residential settings for people with autism are an opportunistic site for therapeutic programs to be established and maintained. Another example of an effective intervention that can reduce challenging behaviors in an ideal residential setting is specialized therapies. Deep touch pressure has been shown to be beneficial in decreasing agitation and distress in people with autism (Blairs, Slater, & Hare, 2007). A residential setting can improve

the quality of life for a child with autism by offering specialized treatments on a regular basis that can reduce negative challenging behaviors.

Campus-style housing offers many solutions to problems that children with autism face, including sensory-based treatment programs, on-site therapeutic services, and a caring environment that enables a child with autism to thrive. Campus-style living for people with autism is not new, other states and countries support this living arrangement for people with autism. The hopes are that if more options for improved living situations become available for children with autism, then even more options will form organically to pave the way for improved living situations for adults with autism as this population ages (End of the Spectrum, 2013; Shumaker, 2012; Siaperas & Beadle-Brown, 2006).

### **A Difficult Decision with Hopeful Outcomes**

New research offers valuable evidence on why a parent places their child with autism into a residential setting. As many as 75% of families of children with autism are described as being able to cope with the demands of caring for a child with autism, whereas the other 25% are left in a dire state of being unable to cope with the challenging behaviors that children with autism have (Corman, 2009). According to Grassie, the parent of a 13-year-old son with autism, “You slowly go insane... the economic impact is less severe than the emotional impact” (personal communication, October 28, 2013). When life becomes so stressful for families that they are no longer able to function, the nightmare of placing a child with autism in a residential setting turns into a reality (Corman, 2009).

Serious and difficult to treat aggressions can be a contributing factor to moving a child from a family home and into a residential setting. Making the decision to transition a child with autism into a residential setting is not an easy one, yet for some families there can be positive

results from doing so. Studies show that there are lasting benefits to placing a child with autism in quality, out-of-home, placement including “learning new skills, acquiring new capabilities... increased confidence and independence... more structure [and] access to better program-based services and activities.” However, some families report feeling judged when seeking support from clinicians, educators, funders, and policy makers. For this reason it is necessary to offer interventions to improve quality of life, including viable living options, to families and children with autism (Hodgetts, Nicholas, & Zwaigenbaum, 2013).

Previous research shows that families who have a child with autism who lives outside of the home often still have “an impressive amount of continued contact” with their son or daughter (Krauss, Seltzer, & Jacobson, 2005, p. 118). Additionally, the combined use of multiple interventions enhances quality of life across the life-span for staff, people with autism, and their families. Though the decision to move a child into a residential setting can be a gut-wrenching one, often times the decision works out to benefit both the child with autism and their family (Chiang & Chen, 2011; Corman, 2009).

### **Efforts to Improve Living Situations for Children with Autism**

Families of children with autism are aware of the needs of their child, but translating those needs into a language that society responds to can be a challenge. Voicing the insurmountable challenges that families face when raising a child who has autism is vital to improve living options for children who have autism. The needs of these families must be heard for legislative action to occur (Beals, 2003; Minnesota Department of Human Services, 2013).

### **Individual and Family-Driven Movements to Promote Change in Society**

Individuals and families who are passionate about improving quality of life are the epicenter of change in a community that has weak supports available for children who are

severely impacted by autism. Families care a great deal about their loved ones, yet raising a child with autism “requires more time and stamina than most parents have” (Beals, 2003). For some families, encountering endless roadblocks on the journey of raising their child with acute special needs has led them to act by advocating for change (personal experience).

Movements started by families to promote quality of life for people with autism occur globally. In Europe, for example, parents have shaped public policy which directly affects organizations that serve people with autism (Chamak, 2008). Closer to home in Minnesota, parents at the End of the Spectrum are working to change legislation with the end goal of creating replicable campus-style housing as a way to improve the quality of life for children with autism and their families (End of the Spectrum, 2013).

Individuals with disabilities play a key role in voicing their needs to a broader audience. Advocating Change Together (ACT) is a group of people with disabilities in Minnesota who have come together to take risks, organize, and lead others to fight oppression and change society to accommodate people with disabilities (Advocating Change Together, 2013). Groups like ACT are important because many people with autism do not have the ability to speak up for themselves, so being supported by other people with disabilities can help give a strong voice to those otherwise unheard.

Family members, namely parents, of people with autism are passionate advocates for increasing and improving services available to people with autism. Parent advocacy groups have formed to lobby congress to improve funding for research to identify the cause of autism and also to increase services available to people with autism and their families (Sack, 1999). Families play a key role in advocating for viable residential options for people with autism, as they are the movers and shakers to improve services and residential options for people with autism.

### **Outside Support Needed by Families to Promote Change in Society**

Families play a pivotal role in promoting change in society by being knowledgeable of best practices of living situations that support a child with autism, stemming from their own personal experiences. A “person-centered” paradigm looks to individuals and families for expertise in ways to support a person with autism. Securing long-term housing and funding services presents numerous obstacles. Families can play a direct role in engaging more members of the community, including key stakeholders, to promote positive change, including increased services available, for children with autism. Showing that a serious problem exists, asking for action, increasing outlets to get messages across, and the snowballing of messages delivered are all ways that families of children with autism are able to engage outside support in a community which can spark a movement for change (Beals, 2003; Chamak, 2008; Downie, 2008).

Research shows that it is possible to be an involved parent when their child lives outside of the family home in a residential setting (Corman, 2009). When communities are strengthened by improved living options for children with autism, parents feel better about their decision, themselves, and their place in society. According to Corman, supporting families of children who are placed in residential settings allowed them to “reclaim their decision to place as morally acceptable and responsible by locating it within a culturally acceptable province (2009).

This change in attitude addresses core social justice issues by demonstrating that families of children who live in residential settings are equal to families whose children remain in the family home. Corman (2009) adds that this research can assist policy-makers whose job it is to improve services to provide equal rights for people with disabilities, such as autism. Social workers are positioned to open up lines of communication between policy makers, individuals

with autism, and those who support people with autism, including community members, family members and staff in residential settings.

### **Informing Policy Makers**

Policy makers are key players on legislation for residential options for people with autism and services available to people with autism is a major political issue. There is significant controversy regarding policies to allocate funding for and delivery of services to people with autism and their families. Because the cause of autism has not yet been determined, there is significant evidence showing the need to determine “causal pathways” in order to prevent autism from occurring altogether. Discovering the cause of autism is fundamental. However, the need to support individuals who have autism and the challenges that their families endure to care for their loved one must not be ignored. Competing for where to target funds for research on autism and programs is a barrier to funding quality living situations for people with autism (Volk et al, 2011).

Policy makers face intricate ethical dilemmas as they ponder where to allocate a decreasing supply of funds available to support families affected by autism. Policy makers have access to research on evidence-based practice which informs their decisions on policies which impact people with autism, yet too much regulation can hinder the delivery of effective services available to people with autism (Feinberg & Vacca, 2000). Ultimately, the laws that policy makers decide on have a direct impact on children with autism, their families, and the community.

### **Role of Social Workers**

When parents are first told that their child has autism, their world as they know it can come to a screeching halt. The questions, concerns, fears, and puzzling uncertainties of where to

go next begin immediately. As time goes on, the questions that families have on how to care for their child who is severely impacted by challenging behaviors merely increases (Newsome, 2000). In such a situation, a social worker is somebody whom a family can turn to for comfort, answers, and guidance. Social workers can provide a wealth of knowledge and resources to families who are navigating the challenging pathway to quality residential options for their child with autism (Autism Speaks, 2011). Families affected by autism are an important population for social workers to serve now and in the years to come because of the sheer number of people who have autism, many of whom may benefit from an out of home placement.

Moving into a residential setting can have a major impact on the quality of life for a person with autism. This can be a very challenging time for families as they must make life-altering decisions about where their child will live. Research shows that parents should be heavily involved in this process to ensure that their child's best interests are being met (Krauss, Seltzer, and Jacobson, 2005). Social workers can be useful in connecting families to needed supports during and after residential transitions. Supporting parents through the transitional process of locating an appropriate residential setting for their child and offering continued support for the parents and the individual with autism can be an effective way to increase quality of life for people with autism and their families (Newsome, 2000).

Social workers can lend a hand in educating policy makers on the pressing needs that children with autism have, including increased living options in Minnesota. Though social workers are knowledgeable of how family systems work, it is truly the individual with autism and their family who should "shape the range and types of services they receive" (Feinberg & Vacca, 2000). Because of this, creating a triad of communication between families impacted by



autism, social workers, and policy makers can improve living options for children with autism by raising awareness for this issue (Beals, 2003; Newsome, 2000).

### **Conclusion**

Past, present, and future research on living situations for children with autism is important because of the devastatingly high impact that autism has on individuals, families, and communities. Providing adequate living options and services to children with autism is a core social justice issue that affects not just the child with autism but their family, caregivers, staff, and the community as a whole. Raising awareness of this issue is important for social work practice. Providing adequate housing for underserved populations (e.g. children with autism) is a step towards equality and social justice for individuals, families, and communities that are severely impacted by autism (Social Work for Social Justice: 10 Principles, class handout, September 2012).

The CDC reports that there are still many unknowns when it comes to autism, yet one thing is for sure: “Autism should be considered an urgent public health concern” (CDC, 2012). Social workers can be utilized to address the immediate and long-term housing concerns for parents of children with autism. Social workers can play a key role in supporting children with autism and their families by navigating the daunting disability system together in hopes of finding a living situation that caters to the unique needs of a “one size does not fit all” population of children who have autism. The research questions for the present study are: What are parent’s perspectives of living situations for their child who has severe autism? What are professional’s perspectives of living situations for children with severe they support in residential settings? And, what role do these parents and professionals feel social workers can play in supporting families who are severely impacted by autism as it pertains to living situations?

### **Conceptual Framework**

The conceptual frameworks of the researcher's personal experience, a family systems lens, and an ecological theoretical perspective all play a strong role in the present research. Understanding the barriers, opportunities, and what it means to have quality living situations for children with autism is complicated. Examining frameworks from which social workers can practice from gives greater meaning and clarity when working with clients. Focusing on the systems in which children with autism live in helps to define where society is at with living situations for children with autism and what needs to change. For the present research, the conceptual framework will guide the researcher towards the "types of literature to focus upon, the methods to choose for collecting data, analyzing it, and disseminating findings" (class handout, September 19, 2013).

#### **Personal Lens**

Personal experience of being a personal care assistant (PCA) for a child with severe autism from approximately 1999 until 2008 has shaped my perspective on why having quality living situations available for children with autism is an urgent matter. In 1999, fresh out of high school, I was hired on the spot to be a classroom assistant for children with autism at Fraser Child and Family Center in Minneapolis. Not knowing what I was getting myself into, I stepped into the most chaotic, overwhelming, and mildly dangerous classroom. Here I was immediately drawn to an intense and beautiful girl who was barely four years old and had no interest in me. Mesmerized and confused by autism, I soaked up as much as I could learn about it from weekly classes at Fraser and endless books and articles on "all things autism." The more I learned about autism at Fraser, the less I understood about this debilitating disorder as there is no cure and no easy treatment to address the sensory needs and challenging behaviors for children with autism.

Though unsure of what I was facing, a bond organically formed between this young girl and myself in her classroom, and as a result I was asked by her parents to be her PCA in their home. For the next nine years, I became an intimate member of a household which held a loving family and a child with severe autism who required constant care and supervision around-the-clock. Unfortunately, this young girl was so severely impacted by autism that that at the age of 12 her parents made the all-consuming and difficult decision to move her to residential campus over two hours away and out of state because there were no viable options nearby. Instead of moving on, her parents not only spent nearly every weekend making the long drive to spend quality time with their daughter, but also teamed up with other families who walk in the same shoes and have children with autism to form the End of the Spectrum, a non-profit whose mission is to create replicable campus-style housing in Minnesota.

Seeing the passion and dedication that these families had to improve their own lives, the lives of their children, and the lives of complete strangers who face the same obstacle in life moved me beyond words. It was through this experience that I began to truly understand the struggles and despair of a family impacted by severe autism through the lens of this young girl's family. Witnessing the struggles firsthand that a family with a child who has a severe disability endures prompted me to pursue a Master's degree in social work and to select the topic of the present research so that I could learn how to better serve families impacted by autism and other life-altering disabilities by learning how to navigate the daunting disability system in Minnesota.

### **Family Systems Lens**

The family systems perspective is important to take into consideration when discussing living situations for children who have autism. The family systems perspective looks at the family as a social system, viewing relationships amongst family members as the focus. Each

individual in the family is viewed as being connected to another and the experiences that each individual has directly impacts the entire family unit. Through this lens, when one family member is diagnosed with autism, then the rest of the family feels the effect of the diagnosis. The challenging behaviors that a child with autism has are not one of just experiences felt by the child who has autism, but by the sub-systems in the family unit made up of parents, siblings, grandparents, cousins, and so on. The pains of being severely impacted by autism can be felt by the entire family (Hutchison, 2011).

When change occurs in the family system (e.g. when a child who has autism moves into a residential setting), a ripple-effect occurs. When a child is diagnosed with autism, a breakdown of family systems occurs (Sheryl Grassie, personal communication, October 28, 2013). Personal experience has shown that caring for a child with autism in the family home can break down the family system by encountering problems that are not easily solved. For example, miscommunication among family members can easily lead to a child who has left the home, requiring an emergency 911 call to locate the missing child. Additionally, placing so much required attention on the child who has autism can leave little quality time for siblings or parents to connect without stressors in place. Often times, interventions requiring a social worker or other outside supports are essential to maintaining a healthy and strong family unit (Hutchison, 2011).

### **Ecological Lens**

The ecological theoretical perspective explains how people and environments are deeply engrained with one another. The ecological perspective suggests that social workers must understand that families are affected by the environment and that the environment affects families in order to strengthen both families and their environment. Promoting empowerment to

change for families and promoting change in environment are equally important skills that a competent social worker should possess in order to practice professionally (Gitterman, & Germaine, 1976).

A family's development and their quality of life are greatly compromised when a child in the family has severe autism. According to Gitterman and Germaine (1976), "incomplete or thwarted task resolution at one stage tends to create difficulties in task resolution associated with a later stage (p. 603). This means that if a family's development can be hindered or even halted when a problem occurs, especially when operating in an environment that is not equipped to handle the needs of the family.

The ecological concept can be applied to the present study. When a young child is severely impacted by autism, displays symptoms that negatively impact the family, and if the environment that the family lives in is not equipped to properly cope with the challenging behaviors, then the family unit becomes ill-equipped to handle future dilemmas. If the family is not properly supported, then, according to the ecological systems perspective, the quality of life for the entire family can fall into a downward spiral (Gitterman, & Germaine, 1976). If enough environmental supports are in place for children with autism to live in settings designed to meet their unique needs, then more families and environments would thrive.

## **Methodology**

### **Introduction**

The research questions for the present study are: What are parent's perspectives of living situations for their child who has severe autism? What are professional's perspectives of living situations for children with severe they support in residential settings? And, what role do these

parents and professionals feel social workers can play in supporting families who are severely impacted by autism as it pertains to living situations? The data was collected qualitatively by interviewing parents of children with autism and professionals who support and interact with children who have autism to gain insight on their perceptions of living options for children with autism.

Interview guides containing six open-ended questions were used and the data was analyzed using content analysis. Some of the questions were answered by the open-ended responses given during previously asked questions and some questions were asked out of order to facilitate an easily-flowing interview. The researcher identified common themes and reported findings. The purpose of the interviews was to gain a better understanding of perspectives of living situations for children who are severely impacted by autism.

### **Study Participants**

The populations being studied for the present research are people in the Twin Cities and surrounding communities who are either a parent of or a professional for children with autism. The research participants were recruited through convenience sampling and snowballing. Convenience samples are a group easily accessed by the researcher. Snowball samples are potential research participants that current participants may know from the same population. For example, a parent known personally by the researcher who has a child with autism may know of another parent or professional who is interested in sharing their experiences of parenting or working with a child who has autism (Monette, Sullivan and DeJong, 2008). The researcher has chosen these types of sampling strategies because it is important for the purpose of the research to collect data from people who intimately know a child or family who is severely impacted by

autism and who have witnessed firsthand the barriers and opportunities that living situations have for a child who is severely impacted by autism.

The present qualitative study has six participants ( $n = 6$ ) and were recruited by convenience sampling and snowball sampling. The participants were selected using convenience sampling because they are parents of children with autism or chosen based on their experiences with working in a residential setting for people who have autism or as their field relates to the topic of the present research and were previously known by the researcher. The researcher also utilized snowball sampling by connecting with personal and professional contacts in the Twin Cities to gather additional participants for the present study.

### **Protection and Rights for Research Participants**

The names of the respondents were kept confidential by omitting them from the transcripts, consent forms, and in other sources that contained identifying information. The researcher went through the University of St. Thomas' Institutional Review Board (IRB) in St. Paul, Minnesota, via the researcher's committee chair for the Social Work Clinical Research Project which the present research is taking place. The researcher sent a proposal of the present study, a list of questions for the interviews (attached in appendix C and D), and the IRB informed consent form (attached in appendix A) to the researcher's research committee. In December 2013, the committee chair and two committee members reviewed the proposal, list of interview questions, and the IRB informed consent form for approval prior to the researcher moving forward with the sending the research proposal to the IRB for final approval.

Once the proposal, interview questions, and IRB informed consent form were formally approved by the IRB, the researcher was allowed to contact participants and began collecting data in January 2014. The respondents were informed of the confidentiality of the interview

process, were sent a list of questions to review and consent form prior to the interview, were assured that they could withdraw from the study at any point of the research process, and were asked to be interviewed with an audio digital recorder to ensure accuracy of data collected. All six participants agreed to be interviewed under these terms and signed the IRB's Informed Consent form .

### **Risks and Benefits of Being in the Study**

Precautions used to minimize risk for participants were to inform participants that they did not have to answer any question they did not feel comfortable with, that they could withdraw from the research process at any time, and to provide resources at the time of the interview in a brochure from the Department of Human Services that provides a list of resources for families of children with autism.

If the interview was held at a coffee shop or restaurant, then the researcher offered to purchase a beverage or food item, valued around approximately \$5-\$10, as a kind gesture of thanks for participating in the interview. This benefit was not offered if the interview was held where such items are not available for purchase (e.g. a family home or agency). The study had no direct benefits other than to contribute to the overall effort to improve living situations for people with autism by sharing personal experiences.

### **Confidentiality**

The records of this study were kept confidential by storing all records (i.e. digital recording of interviews and hard copies of interview notes, interview consent forms, and all other documents containing identifying information) in a locked filing cabinet in the researcher's home office. Electronic copies of the interview transcripts were kept in password protected files on the researcher's personal computer. Research participants were identified by a respondent



code, not by name. Any identifying information from the interviews were entirely omitted from the study (e.g. name of participant or name of agency research participant works for, name of child with autism, or name of sibling of child with autism). All records and documents containing identifying information of the research participants from the present study will be deleted and/or destroyed by June 2014.

### **Voluntary Nature of the Study**

Participation in the present study was entirely voluntary. Participants were informed that they could skip any questions they did not wish to answer and could stop the interview at any time. Participant's decision whether or not to participate did not affect participant's current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. Participants were free to withdraw at any time without penalty. Should participants decide to withdraw at a future point in time, data collected from their interviews will not be used.

### **Data Collection**

The data was collected using a list of six open-ended questions prepared by the researcher, and approved by the IRB, as they relate to the participant's experiences and their perceptions of how living situations impact children who have autism and the perceived role social workers play to support families impacted by severe autism. Questions were developed and formulated, with input from the researcher's committee members, to gain a broad scope on the dynamics of living situations for children with autism. Refer to attached appendix C and D for the lists of interview questions. The interviews were recorded with an audio digital recorder with permission of the participants for the researcher to efficiently collect data, transcribe, and use for analysis.

**Setting**

The settings for the interviews were held in private, convenient, and comfortable spaces. The researcher traveled to desired meeting spaces for the interviews, chosen by the interviewees. Interviews were held in private meeting spaces at local restaurants, at a coffee shop, and in the homes of two participants. All settings were agreed upon with the interviewee and provided as much comfort and privacy as feasible.

**Analysis Technique**

The analytic strategy for the present qualitative study was for the researcher to transcribe the interviews and to perform content analysis. Content analysis is described by Monette, Sullivan and DeJong (2008) as “a method of transforming words or other images, from a qualitative, unsystematic form into a quantitative, systematic form” (p. 203). Once transcribed from an audio recording to words in a Word document, the content from each interview was analyzed. Common themes were identified including repeated terminology and concepts that stood out to the researcher as relevant to and important for the present study. The researcher also compared interview transcripts with field notes taken during interviews and identified additional common themes to support the validity and reliability of performing content analysis.

**Strengths and Limitations of Analysis Technique**

Using content analysis to analyze qualitative data makes it possible to categorize elements of the interviews into categories that are applicable and relevant to the present study. In other words, content analysis makes it possible for the researcher to evaluate verbal content. Limitations of content analysis are that an “overlapping” between categories can lead to grey areas of measurement, as well as a decrease in validity and reliability of measured data, due to inexperience the transcriber and coder (Monette, Sullivan and DeJong, 2008).

For the present study, the student researcher has done the transcribing, coding, and content analysis. Because of being a novice researcher, it is possible that errors could have occurred during transcription, coding, or content analysis. It is also important to note that many of the identified themes fell into more than one category. It was the researcher's discretion to insert findings into what seemed to be the most applicable category.

## **Findings**

### **Introduction**

The purpose of these research interviews was to explore perspectives of living situations for children who are severely impacted by autism. The demographics of the participants include six participants. All participants were Caucasian and over the age of 18. All of the participants reside in Minnesota. Four of the six participants were a parent of a child, ranging in ages from 10 to 18 years old, with severe autism.

All four of the parents have either one or two other children (i.e. siblings of a child with autism). Two of the parents interviewed are married to each other. All four parents had moved their child into a residential setting in the past three to six years. Two of the six participants were professionals who work in leadership positions in residential settings for people who have autism and other types of disabilities. For confidentiality reasons, participants will be referred to as Pa1-4 for parents and Pr1-2 for professionals.

The most common and relevant themes identified the present study are described in the following sections: *Part One, Experiences of Raising a Child with Severe Autism in the Family Home: Challenging Behaviors and Joyful Experiences, Parental Stress, and Siblings of Children with Severe Autism.*

*Part Two, Experiences of Raising a Child with Severe Autism in Residential Settings:*

Challenging Behaviors and Joyful Experiences in Residential Settings, Financial Implications, Impact of Staff in Residential Settings, and Second Guessing. *Part Three, Overall Perspectives on Living Situations for Children with Severe Autism:* Ideal Living Situations, One Size Does Not Fit All, Children with Severe Autism Still Need Parents, Public Awareness and Social Workers: Roles and Opportunities. Themes will be reported and discussion of findings will follow.

### **Definitions**

The terms below arose throughout the interviews. For the purpose of the present study, the following definitions are provided for clarity of understanding:

***Professionals:*** Trained professionals with a minimum of a Bachelor's degree who work in leadership positions in residential settings.

***Residential Providers:*** Organizations that offer residential services for children with autism who live outside of the family home.

***Social Workers:*** Graduates of social work programs who are trained to support individuals, families, and communities to improve their overall well-being and to empower themselves (Barker, 2003).

***Staff:*** Paid employees who work in residential setting for children with autism. Though staff must meet minimum state requirements for training, a college degree and previous experience of working with people with autism is not required.

## Part One

### Experiences of Raising a Child with Severe Autism in the Family Home

The following sections describe the respondent's perspectives of living situations for children with severe autism living in the family home.

#### Challenging Behaviors and Joyful Experiences

Several of the respondents simultaneously shared their perspectives of joyful experiences and the challenging behaviors that their children had while still living in the family home.

Pa2 said that her daughter with autism *“was very destructive...constantly getting herself in trouble, constantly at risk, drinking stuff like soap and Windex out of the bottle. It was hard, but she was also very fun, very vivacious, and very giggly. She's fun to watch. She's very smart, very clever and very cute.”*

Pa1 stated that parenting experiences *“are all more intense and difficult; requiring a great deal more of your attention and emotional effort.”* He explained his perspective regarding challenging behaviors and raising children with severe autism:

*“Parents of a severely autistic child live their lives in a defenseless crouch. It's like being in a room full of unexploded bombs. There's a good chance something is gonna happen and there's a good chance something is gonna go off. One of the reasons why an out of home placement is necessitated, especially with severely autistic children, is that they need a degree of structure and calm that no normal family is able to produce, especially if there are other children involved.”*

Pa4 described his child's aggressive behaviors towards himself and others. He said that the challenging behaviors provoked fear in the family home, stating: *“He used to smash his head when he was younger if he was mad, or pinch, but he never got super aggressive until teenage*

*years where he'd actually try to bite you. But he was a high-maintenance happy kid." As Pa4's son grew older, he admitted the fears increased. Pa4 said about his son: "Is he going to come running down the stairs and attack me?"*

Throughout sharing their perspectives on their son's challenging behaviors, Pa3 and Pa4 described their son's general demeanor as *"a happy kid."* They continued to use the word *"happy"* to describe him numerous times throughout the interview. Pa3 said, *"We enjoy having him in our family, because despite his deficits, he's got a funny sense of humor and a neat personality. He's a sweet boy and he can show affection. So I think that's a good asset to have in life."*

Pr1 has observed countless families who have a child with severe autism struggle with day-to-day tasks over the years. She spoke to how challenging it can be to simply run an errand with your child and said, *"Somebody not being able to control their child in a grocery store is not necessarily a bad parent."*

Pa1 concluded his perspective on the experiences of raising his daughter in the family home by saying : *"It has been a joy watching our daughter expressing her individuality. Seeing and learning what she is actually capable of. We always joke, she's ain't dumb, she's autistic!"*

Multiple perspectives of the parents and professionals interviewed described that parenting experiences are far more challenging when your child has severe autism. These challenges were reported as causing an increase in stress, which is described in the following section.

### **Parental Stress**

Most respondents reported that the effects of caring for a child with severe autism around the clock resulted in an unpredictable and unstable lifestyle. All respondents stated that a

significant amount of time and energy is spent focusing on their child's needs and challenging behaviors. All of the parents interviewed discussed feeling stressed out and isolated because of this.

All of the parents reported that stress affected them personally as well as in relationships with and among other family members, friends and coworkers. Pa2 said that she did not always feel understood by other parents whose children do not have autism, and that it was painful seeing other children with higher functioning autism making more improvements than her daughter.

Pa2 went on to describe restless nights as *"the norm"* and *"three and a half solid years of not sleeping consistently."* She described the long-term effects of raising a child with severe autism: *"It's taxing, it's expensive, you can't live normally. The house... we lived in a warehouse essentially. You're buying these cabinets that lock, and you're bolting them against the wall so she doesn't tip them on herself."*

Pa2 explained how their child's autism was harder on her husband, who was a stay-at-home dad. She said he carried the brunt of the stress for caring for their child with autism: *"It was a devastating and emotional toll. My husband was in denial the whole time. It was hard years."* Pa2 went on to say that her husband had committed suicide when their child was five years old. She repeated that *"those were very hard years"* several more times, but also expressed that she and her children are in a better place now, thanks to a supportive family and a good social worker.

Pa3 reminisced about when her son was still living at home and said, *"I remember back then I never made plans. I couldn't make plans."* Pr1 discussed how overwhelmed parents become by the lack of sleep and amount of work it takes to care for a child with severe autism.

She said: *“parents are pretty much heroic in what they do.”* She added that as a professional, she gets to go home at the end of the day, something that parents are unable to do.

Pa4 said *“It gets to the point where you can’t do anything ... I can see why couples get divorced,”* and offered an analogy to explain what it felt like to raise a son with severe autism:

*“I’m in the ocean, treading water, constantly treading water. I can’t stop treading water... if I stop treading, I’m sinking. Sometimes the water would be calmer, and you could tread, but sometimes THERE ARE MASSIVE WAVES! You never could relax.”*

All respondent shared perspectives that detailed intense levels of stress. Most of the respondents reported that raising a child with severe autism is mentally and physically exhausting.

### **Siblings of Children with Severe Autism**

Multiple respondents shared perspectives on challenges that are present with siblings of children with severe autism. All parents in the present study reported that the sibling(s) of their child with autism have experienced negative consequences from living in a home with a sibling who is severely impacted by autism.

Pa1 described the toll that having a child with autism can have on the siblings, and the sacrifices that are made:

*“It’s very tough on any other children in the house, in my opinion, because the autistic child ends up sucking up all of the resources: parental attention, parental energy, parental emotional even-keeledness... Her brother was entering a particularity sensitive time in his life where he would need, or ought to have, more attention than what we were able to pay to him while his sister was in the house. And frankly, our energy levels were waning.”*



Pa4 discussed how their family's dynamics with having two sons with autism and a daughter who did not have autism. He said that when there are other children in the house, you "try to balance it," but the children with autism take up the "mental, physical, spiritual resources." He went on to explain that when their child with severe autism was aggressive, they would tell their daughter to: "Go lock yourself in the bathroom!" He added that with two boys on the autism spectrum, it was like "fire and dynamite" in their house.

Pa3 said:

*"It got really hard. I look back now... it was really, really hard. When you're having a crisis, it was stressful on the other kids. When [child with severe autism] was having a crisis, we drove him up to Fairview one night because we knew they would admit him. The next day I get a call from his sibling's school, and his sibling had a meltdown at school, hitting and throwing things and stuff. I think there might be a connection, our whole family- our whole life is turned upside down, and the stress level... so it was really tough."*

All four parents reported that having a child with severe autism living in the family home takes a mental toll and is stressful for the other siblings in the house.

## **Part Two**

### **Experiences of Raising a Child with Severe Autism in Residential Settings**

The following sections describe the respondent's perspectives of living situations for children with severe autism who currently live in residential settings.

#### **Challenging Behaviors and Joyful Experiences in Residential Settings**

All of the parents interviewed reported that moving their child into a residential setting was the last resort for their family. Most of the parents reported that once their children

transitioned into residential settings, challenges and joys continued for their children and their families.

Pa1 said he and his wife reached the *“heartbreaking conclusion”* to move their child into a residential setting two and a half hours away. He added that it has been fun getting to know his daughter now that they have been able to decompress from the years of built up stress. When discussing his current relationship with his daughter who now lives in a group home he said: *“She’s actually capable of some pretty advanced reasoning in a lot of ways. Getting to know that side of her is easier now that we have her in a good situation. We have a great time with her.”*

Pa1 talked more about his experience of moving his child into a residential setting:

*“I knew it wasn’t necessarily a bad thing. I’m still convinced it was the right thing to do. I believe she was well treated and helped in many ways. And one or the other or the both of us would drive down every Sunday to visit her which again, but every time you left her there she would always watch you leave, either through the window or through the fence, and it was like peeling off a little piece of your heart every time you left.”*

Pa3 described her dedication as a mother and how she felt when the time came to move their son out of the family home and into a temporary crisis setting:

*“It was the hardest thing I’ve ever had to do. I’m a stay at home mom. My life was so wrapped around that boy. I had a nervous breakdown when that happened. When he went to the hospital, I was like, ‘He’s not going to understand what’s happening. He’s going to be scared, they won’t understand him!’ I used to be like ‘WHO puts their kids in group homes?! How would you get rid of your kid?’ But then I thought, ‘You’re NOT getting rid of your kid!’”*

Pa2 said: *“So it’s been kind of a ride, very rewarding, and she’ll always be my little girl. It’s been fun. I mean, it’s been gratifying to see how much improvement she’s had.”*

Pr1 said that both parents and staff can have positive experiences: *“What brings [parents] joy I think is seeing their child succeed. What gives them joy is being able to be their child’s champion. I think for other caregivers to really respect and honor that, to include them with that experience is really, really important.”*

Pa1 and Pa2 reported that they thought that their children were in good group homes because they offered much of what they could not give at home. The other parents and professionals reported a desire for improved options for residential settings.

Pr2 said *“the lack of planning and the lack of investment of time”* impact quality of life. She said: *“Once those things are in place, you’re going to set your child up for success.”*

Pa3 said that her son currently has a poor quality of life in the crisis setting where he is supposed to be living temporarily but it is turning into another long-term and expensive stay. She said that he has very little freedom, but believes that his quality of life will drastically improve when he lives in a setting where he can be *“self-directed”* and have more choices. She felt that the staff, where he lived prior to being sent to a crisis unit, were always saying *“NO NO NO NO NO NO!”* and that her son is *“being controlled and contained... his default is watching videos. Basically that’s the only thing he has choices for.”* She expressed that these limitations, along with lack of communication with her and her husband, led to the crisis that caused him to be removed from his group home and placed in a psychiatric unit in a hospital.

All of the respondents talked about numerous barriers and opportunities in residential settings that affect the quality of life for individuals with autism and their families.

### **Financial Implications**

All of the parents reported that the costs of raising a child who is severely impacted by autism fall on the responsibility of both parents and taxpayers and “*are immense.*” Pa1 said: “*I am concerned as a citizen for the future, that a four person group home is probably going to be very hard for society to maintain.*”

Pa2 said that the temporary crisis setting her daughter was placed in for a long-term stay was “*an exorbitant amount. I saw the bill for it, and everyday it was \$830 bucks!*”

Pa 4 said that the temporary crisis setting was only supposed to be a three or four week stay for his son, but ended up being an 11 month stay. He said: “*They could have built a mansion [for our son] with the money spent on the crisis stays!*”

### **Impact of Staff in Residential Settings**

The barriers and opportunities of staff in existing residential settings, where their child currently lives or has lived at, were widely discussed by parents and professionals who were interviewed.

#### **Barriers with Staff**

Parents described various barriers they have with their child’s staff in residential settings, including lack of communication and empathy towards parents, untrained staff and frequent staff turnaround. Pa1 stated:

*“The one person who knows what it is that will get this child to stop having a temper tantrum is gone, and so on... and... and those circumstances I’m afraid that the solution that will be reached all too often will be great amounts of medication, just to keep the child tractable, which, you know, I think would be bad (laughter).”*

Pr1 suggested that some staff might take a child's aggressive behavior personal, but that *"it's not personal."* She said this is an important barrier for staff to overcome.

PA4 said that he would like staff to honor parents. He said, *"I don't want to put anybody down, but people work in these fields and they think they know, but even if we are wrong, we're the parents. You let the parents do whatever the heck they want!"* He said that he and his wife believe they know what their son likes and what causes his challenging behaviors, so it is hard when providers act like they know more than they do. He added that he does not always trust his son's providers, and that he is *"at the mercy of these providers."*

All four of the parents interviewed expressed concern that staff in residential settings are not properly trained in working with children with severe autism. Pa4 said that child's staff often just want to get through their shift and frequently play videos instead of engaging them in activities they enjoy.

### **Opportunities with Staff**

All of the participants from the present study reported that staff in residential settings can play a key role in outcomes of success for children with autism. Some suggestions that parents made include training staff and increasing their awareness of what it will look like to work with a child who is severely impacted by autism, and techniques that can help them, including offering choices, being respectful, and believing in that person. Pa1 said: *"You have to have people who know her and understand her needs."*

Pr2 discussed being creative with a staffing pattern that prevents burnout in staff and said that staff can help children with autism *"bloom"* in their living situation by encouraging them to be contributing members in their community and supporting them to find jobs that they can perform.

Pa2 said that her child *“ABSOLUTELY thrives on the structure of the group home... you almost have to have a military type background or something to be organized enough [to keep your child in the family home]. My daughter is a kid that it really does take a village. She really does. She needs, um, to use kind of a vulgar term; she needs fresh meat every shift. Ah, somebody that comes in that’s not been at work, you know they go home for rest and they come and work with my daughter.”*

Pa4 said, *“He gets told ‘No!’ so much... he gets told no so often we have to say sometimes: ‘It’s ok, you can do that!’”* Pa4 said that his son is a *“happy go-lucky kid”* and that some of the staff who work with him enjoy his company. He felt that his son could have a couple staff who are friends with him, and maybe come back to visit someday. He added that having consistent staff is important, and acknowledged that staff will not work at a residential setting forever, but *“stay a year or two while in college.”*

PA3 talked about needing staff who understand her son and are not afraid of him. She said: *“I want people that want to work with him. They know the whole picture. They know that they might get bit, you know, they probably will get bit! But they can see that there’s a person in there. This kid can have joy and a good life!”* Pa3 and Pa3 both stated that working with a person who has autism can be both a challenging and rewarding experience.

## **Second Guessing**

As a result of watching their child have a decrease in challenging behaviors and increase in quality of life, some of the parents brought up thoughts about moving their child back into the family home.

Pa1 told his perspective of the life-changing event of moving his child into a residential setting, two and a half hours away from their home. He described emotions of both relief and

sadness. He said he wondered if their child could move back into the family home because of the decreases in her challenging behaviors. He said:

*“The dark underside is that you then start thinking that maybe you’re wrong having her live away from you and you should bring her back. This is bittersweet in the sense that you start to dream that maybe you could all live together once again, but you realize the reason it goes so well is because she is in a stable and nurturing environment. In fact a lot of the problems, a lot of the troubling behaviors, would come back and we would have a hell of a time dealing with our daughter. And, the outlook is that we are getting old (said with humor).”*

Pa2 described a similar feeling: *“I still have these little slide backs where I’m like, ‘Why can’t I have her at home?’ ‘She does good!’”*

Pa1 provided an analogy that best summed up the phenomenon of what it feels like to move your child out of the family home:

*“When you have depression, you take antidepressants, you stopped feeling depressed and stop taking antidepressants, and then the depression comes back.”*

## **Part Three**

### **Overall Perspectives on Living Situations for Children with Severe Autism**

This final section describes various perspectives on living situations for children with severe autism, including the role that parents and professionals feel that social workers can play in supporting people who are severely impacted by autism.

#### **Ideal Living Situations**

All respondents gave detailed descriptions of their perspectives of ideal housing situation for children with severe autism.

### **Opinions of Ideal Living Situations**

For this portion of the interviews, participants were asked to describe what they thought an ideal living situation look like for their child. All of the parents spent a significant portion of the interview on this topic, and the summaries of their descriptions are as follows:

Pa1:

*“Structure and predictability. School or work programs on the same location. A farm setting where she spends most of their time- this is not to say they never go out in the community, they should go out in the community. Friends. A safe, serene place with people who know what her issues are and who understand her particular quirks. Meaningful activities every day. It is absolutely crucial that family and friends have access. Some of these places feel rather standoffish towards family and friends. I think it’s absolutely crucial that families be as involved in their children’s lives as they can be. And be encouraged.”*

Pa2:

*“In my fantasy world she lives on some acreage, and for financial reasons there’s gonna be other families. I would love to be able to spend late hours with her and be able to sleep in her house sometimes. Outings. Consistency. Probably some gardens are around. My daughter is a really handy kid. She likes to be busy... a swimming pool, very large sensory room, especially in MN (laughs). It would be nice to have some family nights. It would be nice to have a big community room where we can all get together, chat, and hangout.”*

Pa3:



*“A place that he can call his own. Purpose... something he enjoys doing. He needs physical exercise. Fresh air and sunshine. And an area that’s safe for him to do that. He gets so boxed in... if you can change his physical environment, his mental, spiritual, emotional environment can change to be a good thing for him. Plus then he would get the sensory experiences he needs... he would just get a lot of that from nature.”*

Pa4: *“A place out in the country... ability to make decisions... freedom. Consistency and a good provider that will work with him.”*

Both of the professionals emphasized a *“one size does not fit all”* and a *“person centered”* environment when asked what they thought an ideal setting for children with severe autism looks like. Additionally, both professionals said that access to the community was also an important factor. Pr2 said: *“I think every person has something to contribute to their community... there are gifts in every single person, and that if we support them, then they can live in a community where they can give back.”*

### **Perspectives of the Role Staff Play in Ideal Living Situations**

Because of the overlap between describing staff dynamics in current residential settings and in perceived ideal living situations, the comments from parents and professionals regarding staff and ideal living situations is described in part two.

### **One Size Does Not Fit All**

All of the parents and professionals interviewed described the uniqueness and individual needs of children who have severe autism. Pr1 said: *“Number one is that the public really needs to understand, and kids with severe autism are not the same as kids who have high functioning autism.”*

Pa1 was clear in stating that what works for some kids with autism, especially those who are higher functioning, does not work for other kids with severe autism. He said that how much a child can benefit from any type of intervention is “*very unpredictable.*” He went on to say that programs for children with severe autism “*have to be very individual effort. I mean you literally have to get inside of the kid’s head and try to figure out how to open up the little openings that allow them to get around or past the autism so that they can absorb new information.*”

Pa4 described his son’s individual needs. He said: “*We’ve noticed over the years he does better with men. Nothing against women, it’s almost like he doesn’t try as much physical stuff sometimes.*” Pa3 added about their son, while laughing: “*Frankly, he senses fear.*”

Pr1 expressed that an ideal living situation “*has to be individual for the person, and different things work for different people... so often we feel that that there is a perfect model, and I would just say that one size doesn’t fit all... we really need to look at what works for the person.*”

### **Person-Centered Approaches**

The term “person-centered” was used by multiple respondents to describe an approach to working with people with autism in residential settings. Pr1 said being person-centered in residential settings is important for effective care for people with autism. Pr2 said that the person-centered training she has received and implemented as a program manager for a residential program is becoming not only common practice among service providers to people with disabilities, but also the law. She said:

*“I initially only had two hours of person-centered training, then I was introduced to more person-centered training through the University of Minnesota, and incorporated that into my meetings for the people on my caseload.”*

Pr2 reported that, in order to be person-centered when supporting people with autism in a residential setting, families and professionals must be in the mindset that they are on the same team. Pr2 described what communication looks like between professionals and families using a person-centered approach:

*“I’m going to pull from you on your strengths, you’re going to pull from my strengths, and we’re going to work together, ultimately, for your son or daughter.’ And it’s not being in the mentality of me vs. you, or us vs. them. It’s really good to get in that mindset that it’s not about me.”*

Pa1 also said that a person-centered approach is ideal: *“The solution probably is going to have to lie in having some fairly well-trained professionals evaluating the situation on a regular basis and tailoring a program to the child.”*

### **Children with Severe Autism Still Need Parents**

A common theme reported by respondents was that children who have severe autism and move into a residential setting still need their parents, and want to be involved parents.

Pa1 said: *“They still need parents, even if you feel like a lot of your duties have been taken away from you, or removed from your direct responsibility.”*

Pa2 said about her daughter living in a group home: *“It is definitely still parenting. I still raise her of course, but now she’s been in a home for 4.5 years. When you have children, you want to be a mom, you want to be a parent to your children. And I’m still struggling with it, of altering that perception of what a parent looks like.”* Pa2 said another perspective is that *“it is possible to be an even better parent, because at home she wasn’t safe, the family was not safe.”*

Pa3 feared what her son’s life would look like if she was not a part of it. She said that one of her big worries is *“who is going to kiss him goodnight?! He’s used to that... Who’s going to*

*love him, hug him? That's still an important part of his life!"* She said that she and her husband are still going to be active in their son's life once he is settled in a more permanent residential setting.

### **Public Awareness**

All of the parents interviewed reported having more time to network, raise awareness, and advocate more for their child, themselves, and other families in similar situations once their child had moved out of the family home and into a residential setting. Additionally, the two professionals who were interviewed reported dedicating a portion of their work towards learning about and advocating for the needs of and rights for people with disabilities, including autism.

Pa1 talked about advocating for his child's needs through a non-profit, aimed improve living situations for people with autism, after his child had moved out of the family home. Pa2 said she thought it would take more public knowledge, money, legislative action, and cooperation from LOTS of people to have a better living situation for her autistic child. She said that when that happens, she will be able to sleep better at night.

Pr1 said that it is important for the public to understand that the needs of people who are severely autistic are different than the needs of people with autism who are higher functioning. She said that children with severe autism deserve dignity and respect, but are not able to voice their own needs. She questioned if the public even knows what those needs are, and said: *"It's so easy to look at the behaviors and say, 'this person- that's not a person.' I've heard people say those kinds of hurtful things. And that is not the conversation. The conversation is 'Let's figure out what works for that person.'"* Pr1 emphasized the need for public support and an understanding that *"one size doesn't fit all"* means that the system needs to offer greater

flexibility to families. She also said that we must not shame parents whose children have higher needs.

Pa4 said: *“The system needs to be fixed so he doesn’t go to an ER. They need more crisis units for autism. And they need to be available, because right now they send you to a psych hospital.”* Pa3 expanded on this by saying that there are options, but *“we just need to know about these different programs we would need to know to get our son a place.”* She said: *“We’ve fought harder battles than this!”* Pa4 followed up by exclaiming with a hopeful attitude: *“The laws have actually changed for the better. We didn’t know there was another option than a group home. The options are expanding... our ideal can be achieved!”*

Perspectives from all of the respondents indicated that raising awareness is very important to effectively supporting children with severe autism and their families.

### **Social Workers: Roles and Opportunities**

The present study is aimed at increasing understanding living situations for children and families who are impacted by autism.

When discussing the role that social workers can play in supporting children who have severe autism in a residential setting, Pr2 said that social workers can educate staff about how to effectively support an individual in a residential setting. She said: *“In order to create someone’s successful living situation; it all comes from the planning that goes into it. If you take time to get together with multiple content experts, then you’re setting them up for success!”* Pr2 said that social workers can be the educators for person-centered approaches to care, about housing options, and about being creative.

Pa1 also discussed the role that social workers can play in supporting families who have become *“extraordinarily isolated”* due to the *“day-to-day and minute-to-minute challenges”* of

raising a child with autism. He said: *“A mother may find that, the only adult contact she may have, aside from her spouse if she has one, is a social worker.”* He shared his view on the role of a social worker:

*“The first job for a social worker is to be a provider of information of what is available, and information that none of these problems is unique to you. Other people have had these problems, and here’s how some of them deal with them. [A social worker’s] main job is a source of information and a navigator that operates within a structure of some sort. A social worker will ideally navigate to a desired result that everybody can live with.”*

Pa4 suggested that social workers should educate themselves so that they can piece various programs and funding options together to best suit individual’s and family’s needs.

Pa2 said she knows another family who has a *“SEVERELY autistic kid,”* and that the mother has frequent suicidal thoughts. She said that the mother is extremely isolated and does not want to place her child in a group home. Pa2 said she understands this mother’s guilt, but feels that the child may thrive if the mother feels more supported, and that a social worker can be this support. She said about her own situation: *“We had a very good social worker. I did not realize how good she was until after my husband had gone. A social worker can educate parents and help them break free from old patterns, think outside the box, and reframe their thinking.”* She said that her social worker takes time to explain options, *“goes to bat”* for her child to advocate for her needs, and introduces new ideas. She felt that being a social worker can be overwhelming, so a social worker should *“ask lots of questions, use a lot of resources, and talk to people who know the system a little better than you.”*

Pr1 said that it is most important for social workers to listen to their client's needs and to advocate for the family's needs, rather than imposing "*predetermined ideas*" on their clients. She explained:

*"In the industry, this is something we do so often. We say 'ok, this is what should work for you,' and you need to stop doing that. We really need to figure out how to be advocates for what people need and set our own egos and agendas aside. It's really hard to systematize individuality. The thing that concerns me the most with people who have severe autism is that, and other people with severe disabilities, is that really, there's not a lot of money in that, there's not going to be a big boom of people that's coming into that, and yet, these are the people, in my mind, that are the most vulnerable and need the most support. So that's where we need to be putting effort."*

All respondents reported that social workers can be a key player in supporting children with severe autism and their families. Most respondents emphasized that parents know their children best, and social workers can be connectors of resources and advocates for educating the public regarding their client's needs.

## Discussion

The research questions for the present study were: What are parent's perspectives of living situations for their child who has severe autism? What are professional's perspectives of living situations for children with severe they support in residential settings? And, what role do these parents and professionals feel social workers can play in supporting families who are severely impacted by autism as it pertains to living situations? In this section, findings will be explained and were found to be both similar and contrasting to previous research, and some new themes emerged. Strengths and limitations of the present study and implications for social work practice, as well as suggestions for future studies, will be discussed.

Categorizing some of the common themes was difficult because of the overlap of information shared by the respondents. Because I did not want to lose the tone of what a respondent was trying to say, I tended to pick a category that most matched the theme. For example, it is noticeable that some of the categories include both problems encountered and kind sentiments about children with autism. An outcome of these perspectives is that having a child, or supporting a child, who is severely impacted by autism has many ups and down. And often times, they can occur simultaneously. For this reason, some common themes were dispersed under a variety of headings.

Major findings from the present study are: 1) Challenging behaviors in children with autism increase parental stress and isolation. 2) Barriers and opportunities with staff are present in residential settings for children with autism. 3) Parents described a vision of an ideal living situation for their child; a "one size does not fit all" theme emerged. 4) Public awareness is essential for children with severe autism and their families. And 5) Suggestions for social workers who support children with severe autism and their families.



### **Challenging Behaviors in Children with Autism Increases Parental Stress and Isolation**

Previous research shows that the parental stress levels for raising a child who has autism is higher than any other disability (Mancil, Boyd, & Bedesem, 2009; Dabrowska & Pisula, 2010). Raising a child with severe autism was found to compromise physical and mental health, all while draining the family's resources (Bennison, 2012). Results from the present study support these findings. Respondents shared that raising a child with severe autism takes a physical, mental and emotional toll.

Research found that when a child displays aggressive and other dangerous challenging behaviors as a result of having autism, their access to services including treatment, learning opportunities, and other daily activities becomes very limited, thus increasing stress, negatively impacting interpersonal relationships, and decreasing hope for their family members (Hodgetts, Nicholas, & Zwaigenbaum, 2013). Parents in the present study reported similar perspectives, and described how their children's challenging behaviors intensified stress and isolating factors.

There were limited findings from previous studies showing the joys and happiness that parents experience with their child with autism, however perspectives from the present study demonstrate how closely intertwined challenging behaviors are with the joy and fulfillment that parents feel when raising a child who has severe autism.

Both previous research and the present study is that the more severe the negative behaviors of a child with autism are, the more likely their family is to make the decision to move the child into a residential setting (Corman, 2009). All of the parents shared the common experience of raising a child with severe autism in the family home, and then reaching the point where keeping the child in the family home was no longer a safe option, for both the child with autism and for the family members. A common theme from the findings was how stressful

situations play into why a parent moves their child out of the family home, and how it affects the whole system. *“Flying by the seat of your pants”* was an analogy used by a parent to describe how life went on when her child still lived in the family home. For all parents interviewed, making the decision to move their child into a residential setting was a painful decision and experience.

Another commonality between the present study and previous research is that many children who would have been placed in residential settings are then hospitalized in psychiatric hospitals or crisis settings because the residential settings they live in are not structured to support the individual needs and challenging behaviors of children who are severely impacted by autism (Hodgetts, Nicholas, & Zwaigenbaum, 2013; Krauss, Seltzer & Jacobson, 2005). Parents in the present study urged to have better residential options for their children with severe autism.

### **Barriers and Opportunities with Staff are Present in Residential Settings**

The personal account of a residential provider supporting an individual with autism to feel useful in his community, shows that it was not only the individual with autism who benefited from this experience of working in the community, but also his staff and possibly his family. This is consistent with previous research that says: “multiple interventions enhances the quality of life across the life-span for staff, people with autism, and their families (Chiang & Chen, 2011; Corman, 2009).

Results from the present study show that parents can be a resource for staff. Some parents shared that they know their child best and can be a voice for their child. Two of the parents interviewed emphasized needing to have more communication with their child’s group home staff, and that staff need to be better trained to not just get through their shift by playing videos

and limiting choices. Based upon these observations, it seems like there is a need to increase quality and competency of staff who work in residential settings.

According to one of the professionals interviewed, parents do not get a break when their child is still living in the family home, but staff can detach and go home at the end of the day to recharge. Another professional seemed dedicated to learning about person-centered approaches to working with people with disabilities. These dynamics can benefit children with autism who live in residential settings by having energized and skilled people caring for them. Overall, there seemed to be strong sentiments from the people interviewed that staff can have a big influence on the day-to-day activities and quality of life for children with autism living in residential settings.

### **Parent's Vision of an Ideal Living Situation for their Child**

Previous studies show that living situations can improve quality of life for people with autism by addressing unique sensory, emotional, and physical needs, thus reducing challenging behaviors and costly interventions (Brand, 2011; Feinberg & Vacca, 2000). Parents and professionals interviewed have similar responses, and offered perspectives on how to work on having some of their child's need met.

When describing their vision of an ideal living situation for their child, some commonalities among all respondents included meaningful activities, plenty of outdoor space, consistency, friends, structure and predictability, space for families to gather, and purpose.

Another finding was that parents still want to be a parent when their child moves of the family home and into a residential setting. Creating spaces in residential settings for families to spend time with their child with autism can improve overall quality of life in living situations.

What works for some people with autism does not work for others, especially if they are more severely autistic. “One Size Does Not Fit All” was another commonality between previous research and the present study. Person-centered values seem to be an effective approach for a “one size does not fit all” population (Beals, 2003; Chamak, 2008; Downie, 2008). A previous study explained that the ability for a residential setting to meet the many needs of autism “varies from child-to-child, and also varies by each home or residential setting, which is important to consider when describing what a quality living situation looks like” (Feinberg & Vacca, 2000).

Many of the parents interviewed desired similar environments when they describe what they felt was an ideal living situation for their child, however they all described, in greater detail, individual preferences and differences that only a person-centered environment could offer. For example, a parent shared that his child is extra sensitive to people’s emotions, so when staff are trained to know that, and like him enough to not push his buttons, even if they’re having a bad day, staff are gonna leave that at the door and just have a good time with child. This is just one example of being person-centered, but really, the possibilities seem endless to be person-centered in residential settings.

### **Public Awareness is Essential for Children with Severe Autism and their Families**

In order for all of these visions of what it takes for ideal living situations to be achieved, more people need to become more informed of why more ideal living situations for people with autism should be available. This seems especially pertinent for all families affected by autism, because according to several respondents, Minnesota has limited living options for people with severe autism.

According to previous research, “families care a great deal about their loved ones, yet raising a child with autism requires more time and stamina than most parents have” (Beals,

2003). This is consistent with the findings from the present study. Multiple perspectives from the respondents show that public awareness can open up the door for an overall improved quality of life for people with autism, their families, and the staff who support them.

Additionally, the present study supports previous research showing that many families need more support from the public as they face the undesirable outcome of moving their child into a residential setting due to dangerous aggressive and self-injuring behaviors including violence towards siblings and “bolting” from the family home. For all of these reasons and more, advocating for children with severe autism and their families was described in both previous research and in the present study.

Sharing personal stories with wider audiences (e.g. social workers, tax payers, and policy makers) offers a glimpse into the life of a family who struggles to care for their child with autism with the hopes of gaining more attention to receive increased support and services was also a common theme in the present study and in previous research (Newsome, 2000).

### **Suggestions for Social Workers**

The present study found that social workers who support children with severe autism and their families can benefit from hearing the perspectives of the clients they serve. Most of the participants gave the overall sense that the future is hopeful in terms of improving living situations for their child with autism. However, the roadblocks and barriers are still many. For this reason, social workers can support families who are feeling the ripple effect of having a child with severe autism.

Understanding the role that social workers play in living situations for people with autism was an important factor to this study. A social worker can be an incredible support to families,

and can provide a wealth of knowledge, education, and resources to families who are navigating the daunting disability system (Autism Speaks, 2011; Beals, 2003; Newsome, 2000).

### **Strengths of Present Research**

Strengths of the present research include an overall sense of optimism and hope from all of the respondents who were interviewed which supports the strengths framework for social workers. At the end of one interview the researcher stated: “Well thank you, I feel like we’re ending on a positive note.” Pa3 responded: “Yes, I feel like we’re working towards the same goal!” Another strength was using open-ended questions. Because the respondents were not limited in their responses, the open ended interview format made it possible for the researcher to learn more about perspectives of living situations than expected.

Finally, the researcher for the present study has prior knowledge, experience, and passion around supporting children and families who are severely impacted by autism. This allowed for more informed research questions, along with follow up questions. However, the researcher’s previous experiences with children with autism can also be a limitation, as biases may impact the results from respondents.

### **Limitations of Present Research**

A limitation of the sampling methods are that the participants are not randomly chosen, thus producing a biased sample of parents and professionals who have a strong voice regarding living situations for children with autism. The researcher’s prior knowledge of autism can also be seen as a limitation to the study, as the interviews would have most likely gone differently had the researcher not been informed of the topic. (Clean up this statement)

A small sample size of six participants was another limitation for the present study. Interviewing more parents of children who have severe autism and the professionals who support

them would provide more diversity and valuable input to the overall effort to learn more about individuals who have severe autism and their families.

Because all of the parents interviewed have moved their children into a residential setting, the results were skewed to only show experiences of what life is like for parents who have a child with severe autism living outside of the family home. A greater perspective would have been obtained if parents of children who live in the family home were interviewed.

Another limitation was that all participants were Caucasian, presumably middle to upper class. Because people of all races, ages, gender and socioeconomic backgrounds are impacted by autism, it is essential to have more equal representation of respondents from these demographics.

### **Emerging Themes**

A common theme from the present study's findings that had not been uncovered in previous research was "second guessing." It was new for the researcher to learn that most parents feel a sense of confusion and wonder about moving their child back into the family home after they had successfully transitioned into a residential setting. Though this seems to be common sense that a parent may want their child back in the family home, exploring these dynamics in greater detail would benefit the overall cause of learning about perspectives of living situation for children with severe autism. For example, it is possible that a child with autism could move back into the family home and thrive with proper supports, whereas another child may revert back into unsafe and challenging behaviors. Supporting families as they have doubts about their child's future could be a topic for future research.

Another new theme that emerged for the research was "children with autism still need parents." Though it is apparent that children with autism still need their parents, there was a large

emphasis from all parents interviewed that they still wanted to maintain a strong parent-child relationship once their child was living in a residential setting outside of the family home. Many of the responses from describing an ideal living situation outside of the family home detailed physical and emotional space for parents to spend time with their child in. Historically, children with disabilities were abandoned by their families and grew up parentless in institutions (Shapiro, 1994). The responses from the parents indicate that many advances have been made in this area, but there is still a long way to go for families to feel fully included in their child's residential setting.

### **Implications for Social Work Practice and Suggestions for Future Research**

According to the Centers for Disease Control (2012), "autism should be considered an urgent public health concern." The desire to increase viable residential options for children with severe autism is a pressing and complicated matter. As our population of children with autism ages, the need for residential options increases (Chamak, 2008). It is beneficial to understand the opportunities and barriers to licensure and funding for viable residential options for people with autism. Because of this, future studies should involve policy makers who shape legislative action.

Individuals who have autism, and their families, play a key role in advocating for needed supports and services (Downie, 2008). Exploring the complicated dynamics of why a parent would need a more ideal living situation for their child outside of the family home may help increase empathy and decrease stigma for families who are deeply affected by autism. Overall, it seems like a person-centered approach is a valued means to address the 'one size does not fit all' paradigm. Pr2 stating that "It's not all about me" seemed to be an important finding for social workers and other professionals who support children with severe autism to be aware of. Pr1's



sentiment of not “taking it personally” seems to be an effective way to remain calm when supporting a child who has severe autism.

Future studies could interview people who interact with people who have autism as well as people who do not interact with people with autism (e.g. policy makers) but make decisions on laws and funding that affect people with autism. Casting a wider net for a more diverse sample will provide greater insight and understanding of how a viable residential setting impacts the quality of life for people with autism and their families. Additionally, all of the parents interviewed displayed varying levels of resilience in their families, and some more so than others. Future research should further explore the coping mechanisms that resilient families utilize.

### **Conclusion**

The perspectives of parents and professionals were essential to learning more about the needs of families in our communities. The overall finding from this study was that children who have autism and fall on the severe end of the spectrum lack adequate options for a living situation that addresses their unique sensory and structure needs. Inadequate housing denies a person their basic human rights. Social workers are at the front lines of fighting for social justice and can be liaisons between people impacted by autism and the community. A social worker can be utilized to address the immediate and long-term housing concerns that parents have for their children with severe autism. Social workers can play a key role in supporting children with autism and their families by navigating the daunting disability system together in hopes of finding a living situation that caters to the unique needs of a “one size does not fit all” population of children who have autism.

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**Appendix A****CONSENT FORM  
UNIVERSITY OF ST. THOMAS****MSW CLINICAL RESEARCH PROJECT:  
Perspectives on Living Situations for Children with Classic Autism**

546611-1

I am conducting a study about perspectives on living situations for children with autism who fall on the severe end of the spectrum. I invite you to participate in this research. You were selected as a possible participant because you are a parent of a child with autism or because of your experience working with people who have autism in residential settings. Please read this form and ask any questions you may have before agreeing to be in the study.

This study is being conducted by: Meghan Constantini, a graduate student at the School of Social Work, Catherine University/University of St. Thomas and supervised by Dr. Katharine Hill and the IRB.

**Background Information:**

The purpose of this qualitative study is to interview parents of children who have autism and professionals who support children with autism in residential settings. The aim is to understand what their perspectives are of living situations for children who are severely impacted by autism and the role that social workers have in supporting families of children who are so severely impaired by having autism that the family is contemplating moving their child into a residential facility or have already done so. By gaining wider perspectives from first-hand accounts of a "one size does not fit all" diagnosis of autism, the researcher is hoping to increase awareness and support for families who face unimaginable challenges of raising a child whom they love unconditionally and may have an increased quality of life if they can live in a setting that can meet the needs of children who are significantly impacted by autism.

**Procedures:**

If you agree to be in this study, I will ask you to do the following things: Answer approximately 8 questions pertaining to experiences of knowing a child who has autism, living situations for children who have autism, qualities of parents who have children with autism, and the role social workers may play in supporting families impacted by autism. The interview will take place at the desired location of the interviewee, should take approximately 45-60 minutes, and will be recorded with a digital audio recorder.

**Risks and Benefits of Being in the Study:**

The study has minimal risks, including psychological stress due to discussing challenges topics. Resources with support for people impacted by autism will be provided to participants at the time of the interview. If the interview is held at a coffee shop, then the researcher will offer to purchase a beverage or bakery goodie, valued around approximately \$5, as a kind gesture of thanks for participating in the interview. This benefit will not be offered if the interview is held where such items are not available for purchase (e.g. a meeting room in an agency). There are no other direct benefits to participation.



**Confidentiality:**

The records of this study will be kept confidential by storing all records (i.e. digital recording of interviews and hard copies of interview notes, interview consent forms, and all other documents containing identifying information) in a locked filing cabinet in the researcher's home office. Electronic copies of the interview transcripts will be kept in password protected files on the researcher's personal computer. Research participants will be identified by a respondent code, not by name. Any identifying information from the interviews will be entirely omitted from the study (e.g. name of participant or name of agency research participant works for). All records and documents containing identifying information of the research participants from the present study will be deleted and/or destroyed by June 2014.

**Voluntary Nature of the Study:**

Your participation in this study is entirely voluntary. You may skip any questions you do not wish to answer and may stop the interview at any time. Your decision whether or not to participate will not affect your current or future relations with St. Catherine University, the University of St. Thomas, or the School of Social Work. If you decide to participate, you are free to withdraw at any time without penalty. Should you decide to withdraw, data collected about you will not be used.

**Contacts and Questions**

My name is Meghan Constantini. You may ask any questions you have now. If you have questions later, you may contact me at 651-336-2273 or my professor, Dr. Hill, at 651-962-5809. You may also contact the University of St. Thomas Institutional Review Board at 651-962-5341 with any questions or concerns.

**You will be given a copy of this form to keep for your records.**

**Statement of Consent:**

I have read the above information. My questions have been answered to my satisfaction. I am at least 18 years of age. I consent to participate in the study and to be recorded with an audio device.

**Anonymous**

\_\_\_\_\_  
**Signature of Study Participant**

\_\_\_\_\_  
**Date**

**Anonymous**

\_\_\_\_\_  
**Print Name of Study Participant**

**Meghan Constantini**

\_\_\_\_\_  
**Signature of Researcher**

\_\_\_\_\_  
**Date**

**Appendix B**

University of St. Thomas IRB

January 7, 2014

To whom it may concern,

Let this letter serve as confirmation that *The End of the Spectrum, Inc.* including myself as executive director and members of our board, have given permission to Meghan Constantini to utilize us as a resource in finding subjects to interview for her master's thesis research. It is my understanding that she will be recruiting approximately 3-5 parents and 3-5 professionals through our contacts in a snowball sample fashion. We are aware of and supportive of her research and happy to help.

Warm Regards,

*Sheryl Grassie*

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## Appendix C

### **Questions for Interviews with Parents of Children with Autism**

- 1) Tell me about your personal experience of raising your child who has autism (share your story).
- 2) Will you describe your opinion of an ideal living situation for your child?
- 3) Does your child live in an ideal setting? If not, skip to question 4.
- 4) Besides money, what would it take for you to achieve that ideal setting?
- 5) What do you do your best at, or what are your successes, as it pertains to your child living at home or in a residential setting? What about this gives you joy?
- 6) What are your biggest road blocks as it pertains to your child living at home or in a residential setting? What hurdles do you encounter?
- 7) What role do you think social workers can play in supporting your family regarding ideal living situations for your child?

Examples of follow up questions: What is the age of your child? Siblings? What is the residential situation for your child, past and present? What are some typical behaviors of your child? What is your opinion on the pros and cons of family homes, group homes, or institutions for your child or other children with severe autism as a living arrangement? What do you want most for your child, given their diagnosis of autism?

## Appendix D

### Questions for Interviews with Professionals

- 1) Tell me about your personal experiences of working with children who are severely impacted by autism.
- 2) Will you describe your opinion of an ideal living situation for children who have [severe] autism?
- 3) In Minnesota, what ideal living options, outside of the family home, are you aware of for children with classic autism?
- 4) Besides more money, what do you think it would take for there to be more ideal living situations available for children with autism in Minnesota?
- 5) What do parents do best, or what are their successes, as it pertains to their child living at home or in a residential setting? What about this gives them joy?
- 6) What are parent's biggest road blocks as it pertains to their child living at home or in a residential setting? What hurdles do they encounter?
- 7) What role do you think social workers can play in supporting families regarding ideal living situations for their child?

Examples of follow up questions: What, if any, experiences have you had working in residential settings for children with autism, past and present? What are some typical behaviors of the children you see? What is your opinion on the pros and cons of family homes, group homes, or institutions for children with severe autism as a living arrangement? What do you want most for children who are diagnosed with autism and fall on the severe end of the spectrum?