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THE IMPACT OF AUTISM SPECTRUM DISORDER ON FAMILY

A MASTER'S THESIS
SUBMITTED TO THE FACULTY
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BY
CHRISTA R. SKITSKO

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THE IMPACT OF AUTISM SPECTRUM DISORDER ON FAMILY

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APPROVED

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Abstract

As the prevalence of Autism Spectrum Disorder (ASD) continuously increases, more individuals and their families are impacted. Parents may be significantly affected by raising a child with an ASD diagnosis due to increased stress from the diagnostic process, financial strain, navigating challenging behaviors, decreased marital and relationship satisfaction, parental burnout, and mental health-related concerns. The diagnosis may also impact siblings of children with ASD. The symptoms and characteristics of a child with ASD can directly impact sibling relationships. Additionally, marital discord, genetics, age, gender, and birth order may influence the relationship between the child with ASD and their siblings. Siblings of children with ASD may also experience mental health-related concerns and difficulties with peer relationships. However, supports can be provided to help families and improve their quality of life. The guiding research question for this thesis is: What is the impact of Autism Spectrum Disorder (ASD) on family? The first area of research is the specific impact ASD has on parents. The second area of research is the impact ASD has on the siblings of children diagnosed. Lastly, the third area of research is on the support that can be provided for families navigating the challenges of having a child diagnosed with ASD.

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CHAPTER I: INTRODUCTION

Introduction

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability that impacts about 1 in 36 children from all racial and ethnic backgrounds (Centers for Disease Control and Prevention [CDC], 2023b). ASD primarily impacts a child's communication, behaviors, and interactions with others. Although signs and symptoms of ASD can be seen in children at any developmental age, typically an ASD diagnosis is considered most reliable at the age of 2 years or later (CDC, 2023b). According to the Diagnostic and Statistical Manual, Fifth Edition (DSM-5), to meet diagnostic criteria for ASD, individuals must show deficits in specific categories (American Psychiatric Association [APA], 2013). The first deficit category is social communication and social interaction. The second deficit category for diagnosis is restrictive or repetitive patterns of behavior, interests, or activities. For a child to meet the criteria for an ASD diagnosis, these deficit areas must impact the child's daily functioning. They must also be seen in the early developmental periods of the child's life; the signs cannot be attributed to an intellectual disorder or global developmental delay, and the deficits must impact multiple areas of the child's life.

The first category to assess an individual for ASD is social communication and social interaction. According to the DSM-5, a child must meet all three criteria in this section to qualify as having a deficit in this category (APA, 2013). The three criteria assess social-emotional reciprocity, non-verbal communicative behaviors, and deficits in building, maintaining, and comprehending relationships. These deficits in social communication and social interaction can be seen in children in various ways, including limited eye contact, lack of facial expressions, limited interactions with others, and showing no response to name calling. Other signs and symptoms of social communication and social interaction delays are limited sharing of interests, inability to participate in a reciprocal conversation, difficulties adjusting to different environments, difficulties engaging in imaginative play, and limited understanding and use of body language (APA, 2013).

The second category used to diagnose ASD is restrictive or repetitive patterns of behavior, interests, or activities (APA, 2013). According to the DSM-5, a child must meet two out of the four criteria to qualify as having a deficit in this category. The first criterion in this category assesses stereotyped or repetitive movements, speech, or use of objects. The second criterion is ritualized patterns of behavior, resistance to change, or persistence in sameness. The next criterion is restricted, fixated interests, and the final criterion is sensitivity to sensory input or unusual sensory interest. These deficits in restrictive or repetitive patterns of behavior, interests, or activities can be seen in children in various ways such as when children line up objects, repeat certain words or phrases, follow specific routines, or particular body movements, like rocking or hand flapping (CDC, 2023b). Other signs and symptoms of restrictive or repetitive patterns of behavior, interests, or activities are rigid thinking, fixation on unusual objects, lack of response to pain or temperature changes, or interest in excessive smelling, touching, or visual stimulation (APA, 2013).

The prevalence of ASD has been gradually increasing. As previously stated, the most recent study on the prevalence of ASD in the United States reported that in 2020, one in 36 children had a confirmed ASD diagnosis (CDC, 2023b). In comparison, in 2000, 1 in 150 children had a confirmed ASD diagnosis. CDC data (2023b) shows that the prevalence of ASD can vary by race and ethnicity. Non-Hispanic White children had the highest rate of diagnosis prior to 2014. By 2020, the percentage of Black, Hispanic, and Asian or Pacific Islander children diagnosed with ASD was higher than Non-Hispanic White children. ASD prevalence varies by sex as well. For example, boys are four times more likely to be diagnosed with ASD than girls. This trend of boys having a higher prevalence than girls has been consistent in CDC (2023b) data since 2002. Improved societal awareness, screening procedures, and access to support and services may be reflected in the increase in prevalence. This data reflects children with a confirmed ASD diagnosis, ASD classification in special education, or children whose records indicate an ASD medical billing code. Therefore, this data may underrepresent the number of children in the United States with ASD. This data does not consider the children with ASD symptoms that have not been diagnosed, assessed for developmental delays, or participated in special education. Therefore, the prevalence of ASD in the United States could potentially be higher.

As the prevalence of ASD continuously increases, more families are being affected by the disorder. A family's quality of life may be impacted when they have a child with an ASD diagnosis. Every family member, adults and children alike, has a significant role in the family unit. When one individual in a family has a disability, it can have a ripple effect on the other family members. Families can be interconnected, with intense interactions and reactions to the environment according to family values (Koukouriki, Athanasopoulou, & Andreoulakis, 2021). When one family member is affected, the entire family system may also be impacted (Minuchin, 1985, as cited in Koukouriki, Athanasopoulou, & Andreoulakis, 2021). This theory can be applied to ASD in a family system. When a child has a chronic illness or disability like ASD, family functioning may be impacted more significantly than the individual diagnosed (Brockberg & Smedema, 2022). Due to the impact an individual's diagnosis can have on a family unit, it is vital to consider the impact on the caregiver and the effect on the quality of life of the entire family.

Rationale

Families who have a child with ASD may face multiple obstacles when trying to receive care (Zablotsky et al., 2014). Families can be burdened with navigating a complex social service and health system to determine an assessment location for the symptomatic child (Mello et al., 2021), taking on the financial cost of assessment (Zablotsky et al., 2014), and coping with the confusion, fear, and denial surrounding a potential diagnosis. Then, once a child has a confirmed ASD diagnosis, family functioning can be severely impacted. Families with a child diagnosed with ASD may experience elevated psychological distress, anxiety, and problematic economic costs associated with intervention programs, and medical expenditures (Brockberg & Smedema, 2022). In addition to the psychological stress parents can experience with an ASD diagnosis, higher levels of marital stress, disciplinary disagreements, and blame are also common (Aylaz et al., 2012; Brisini & Solomon, 2020). Raising a child with ASD can cause more stress for parents in comparison to parents raising neurotypical children or even children with other developmental disabilities (Brisini & Solomon, 2020; Brobst et al., 2009).

The parental stress and demands of raising a child on the spectrum may not decrease as the child ages (Tongerloo et al., 2015). Taking care of a child with ASD is typically a lifelong responsibility that can impact the quality of life of aging parents (Marsack-Topolewski, 2020). A negative relationship can exist between caregiving for a child with ASD and time constraints. These can impact a parent’s ability to engage in social activities, which adversely impacts the quality of life of parents. Specifically, older parents who have a child with ASD may feel isolated from friends and family and feel that the caregiver role negatively impacts personal lives, marital relationships, and work. Although parents may be impacted by an extended caregiver role when raising a child with ASD, the siblings are often involved in the caregiving role as well. They typically adopt the responsibility of being the primary caregiver for the diagnosed sibling in adulthood (Koukouriki, Athanasopoulou, & Andreoulakis, 2021).

Sibling relationships are arguably one of the most influential and intimate relationships an individual will develop in life (Koukouriki, Athanasopoulou, & Andreoulakis, 2021). When a family has a child with an ASD diagnosis, siblings can also be affected by the diagnosis. The diagnosis typically has a positive or negative impact on a sibling relationship; however, the siblings may also experience no significant impact at all. In addition, similar to neurotypical sibling relationships, positive and negative experiences and behaviors coexist in a sibling relationship and cannot be discussed separately (Laghi et al., 2023). Current research shows inconsistent findings on the impact ASD diagnosis has on siblings. Iannuzzi et al. (2021) discuss that siblings may experience a range of emotions concerning the sibling with ASD. A sibling on the spectrum can create new learning opportunities to develop acceptance, respect, empathy, and compassion; it can also create a sense of pride and exciting shared experiences between the siblings (Laghi et al., 2023).

Research also shows that an ASD diagnosis can have a negative impact on siblings. Siblings of an individual diagnosed with ASD can have feelings of frustration, annoyance, shame, and embarrassment (Iannuzzi et al., 2021). These negative feelings can primarily stem from the unpredictability of the diagnosed sibling's behaviors, leading to increased anxiety and hypervigilance at home and in public. Behavioral problems like emotional symptoms and conduct problems are related to negative sibling relationships (Laghi et al., 2023). Siblings can also be indirectly affected by ASD diagnosis by the higher levels of parental stress that can occur from an ASD diagnosis. This indirect impact of an ASD diagnosis can cause children to internalize familial conflict, like marital stress, and direct more negative behaviors toward the sibling with ASD, negatively impacting the sibling relationship (Rivers & Stoneman, 2003; Rixon et al., 2021).

The effect ASD has on a family is a critical area of research. The well-being of a family can impact the diagnosed child's growth and development. It is reciprocal as the needs of a child with ASD impact the family system, but, in turn, the health and well-being of the family can impact the success of the child diagnosed. Therefore, problems with a child with ASD may impact the caregiver's quality of life, which in turn can impact the interaction between the caregiver and the child with ASD and then further influence the child's quality of life (ten Hoopen et al., 2019). A family is interconnected, with every person impacting each other. It is crucial to consider what impact ASD has on a family, to identify the effect on parents and siblings, and to determine what support can be provided to ensure that the strength and stability of a family can be maintained while navigating disability.

Definition of Terms

Important terminology used in this paper are:

Autism Spectrum Disorder (ASD): Autism Spectrum Disorder (ASD) is a neurodevelopmental disability that causes problems with social communication and social interaction, and restricted or repetitive behaviors or interests (CDC, 2023b).

Broad Autism Phenotype (BAP): The Broad Autism Phenotype are genetically based autism traits found in family members of individuals diagnosed with ASD (Koukouriki, Soulis, & Andreoulakis, 2021).

Burnout: Burnout is excessive or chronic stress due to the developmental difference and level of care required for a child with a disability (Ardic, 2020).

Challenging behavior: Challenging behavior is defined as an "action or set of actions deemed problematic because it deviates from social, cultural or developmental norms and is prejudicial to the person or the person's social or physical environment" (Rochefort et al., 2023, para. 1).

Comorbidity: Comorbidity is defined as a person who has more than one condition or disease at the same time (CDC, 2023a).

Developmental disability: A developmental disability is when an individual has an impairment in learning, physical, language or behavior (CDC, 2022).

Neurodevelopmental disability: A neurodevelopmental disability is "impairments in cognition, communication, behavior and/or motor skills resulting from abnormal brain development" (Mullin et al., 2013, p. 1).

Neurotypical: Neurotypical can be defined as "someone who thinks and processes information in ways that are typical within their culture" (MediLexicon International, 2022).

Parentification: Parentification is defined as the responsibilities provided to typically developing children with an ASD sibling that are beyond the developmental age (Koukouriki, Athanasopoulou, & Andreoulakis, 2021).

Statement of the Question

The guiding research question for this thesis is: What is the impact of Autism Spectrum Disorder (ASD) on family? There are three primary areas to explore concerning this guiding question. The first area of research is the specific impact ASD has on parents. The second area of research is the impact ASD has on the siblings of children diagnosed. Lastly, the third area of research is on the support that can be provided for families navigating the challenges of having a child diagnosed with ASD.

CHAPTER II: LITERATURE REVIEW

Process and Parameters of Research

The literature and information utilized for this thesis on Autism Spectrum Disorder (ASD) were primarily accessed through research databases, except for information found from the CDC (2023) and DSM-V (APA, 2013). The research databases used to acquire literature and information were ERIC, ProQuest Education Journals, Academic Search Primer, PsycINFO, and ProQuest Psychology Journals. These databases were searched for primarily newer studies and publications from 2018-2023, apart from a few earlier studies. The earliest study utilized in this research paper is from 2003. The keywords used in these searches include “autism spectrum disorder,” “family and autism spectrum disorder,” “impacts of autism spectrum disorder,” “siblings and autism spectrum disorder,” “parents and autism spectrum disorder,” “autism and mental health,” autism and relationships,” “autism and formal support,” “autism and informal support,” “autism and support,” and “diagnosis and an autism spectrum disorder.” This chapter will review the literature on the impact an ASD diagnosis has on families in three main sections: Impacts of Autism Spectrum Disorder on Parents, Impacts of Autism Spectrum Disorder on Siblings, and Support for Families Navigating an Autism Spectrum Disorder Diagnosis.

Impacts of Autism Spectrum Disorder on Parents

Parents are typically the primary caregiver for children with ASD. Due to the impact of the caregiver role, families often experience social, emotional, physical and financial stress (McConkey et al., 2020). Children with ASD often require extensive care, attention, and support from parental caregivers. Raising a child with ASD can affect many areas of the parent’s lives. The parents of children with ASD can have elevated risk factors in the areas of health and well-being in comparison to the parents of children without ASD (ten Hoopen et al., 2019). The areas in the parent's lives that may be significantly impacted by raising a child with an ASD diagnosis include increased stress from the diagnostic process (Roig-Vila et al., 2020), the financial burdens of ASD (Kuhlthau et al., 2014), navigating challenging behaviors (Mello et al., 2021), decreased marital and relationship satisfaction (Brobst et al., 2009), parental burnout (Ardic, 2020) and mental health-related concerns (Dimachkie Nunnally et al., 2023).

The Stress of the Diagnostic Process

Parents may experience stress when they feel that the responsibility and demands of caring for a child outweigh the perceived resources available to them (Mello et al., 2021). Many parents raising a family and caring for a child with ASD feel the responsibility of raising a child with ASD exceeds parental qualifications (Tongerloo et al., 2015). Some parents have a sense of guilt that they are failing as caregivers to the afflicted child and failing the typically developing children as well. The role of parenting can be riddled with stress when raising neurotypical children; however parents may be even more burdened with stress when raising a child with a disability (Shamash & Hinman, 2021).

Stress can occur for parents prior to a formal ASD diagnosis. Roig-Vila et al. (2020) state that many parents feel waiting for a diagnosis is the “most painful time” (para. 35), potentially even more painful than receiving the official ASD diagnosis. Parents may encounter the child's often confusing symptoms without any understanding of what is happening with their child. In the period of time between the initial concerns and the diagnosis, parents can feel a sense of helplessness and frustration. Many parents know that something appears to be different about the child and therefore make a decision to seek specialists for clarity. Additionally, the time frame before a diagnosis is often difficult as many parents struggle to manage feelings of denial. Extended family or friends often detect the first ASD symptoms in a child (Roig-Vila et al., 2020). Parents sometimes ignore the early signs of ASD in a child and do not want to accept that anything could be wrong.

Many parents view the process of finding support negatively due to internal and external reasons (Avery et al., 2022). Some parents struggle because they do not know where to seek help, and some struggle for reasons like waitlists and financial constraints. Stress for parents can also occur before and during the diagnostic process due to the time it may take to receive a diagnosis. Months and years may pass from when the child is identified as having symptoms to when the child receives an ASD diagnosis (Myers et al., 2020). During this extended timeframe, parents may have to discuss and receive extensive information on the child from different service providers. Parents may have to interact with a consultant, have the child undergo multiple medical tests, and then see specialists to attempt to secure a consensus on a diagnosis (Roig-Vila et al., 2020).

During these experiences, parents typically have a range of perceptions of the quality of care they receive. Some parents feel positive about the experiences and report that they were listened to, had enough time to address concerns, and felt like a partner in the care of the child with ASD with the healthcare professionals (Myers et al., 2020). Alternatively, some parents also feel negative about the healthcare experiences. They report that concerns were disregarded, providers lacked knowledge of ASD diagnoses, and they were not considered in the diagnostic process. Some parents have even reported that the diagnostic process was a "deeply traumatic episode" (Roig-Vila et al., 2020, p. 256). Over 70% of families report that the diagnostic process alone is stressful (Myers et al., 2020). For many families, the diagnostic process is challenging, emotionally and mentally, and can cause symptoms of anxiety and depression in parents.

Behavioral, Social and Emotional Challenges

Parental stress may not be alleviated once a child receives a formal diagnosis. After the ASD diagnosis has been confirmed, parents are often placed on another waitlist to obtain early intervention support for their child (Mello et al., 2021). This may be another unknown waiting period where ultimately, the parents may not receive the support or education they wish for the child. Strategies and practices may have to be developed at home by the parents to support the child's needs. Parents also take on many difficulties associated with an ASD diagnosis. They may need to navigate the child's health as well as any developmental, behavioral, and social difficulties (ten Hoopen et al., 2019). This impacts the child but can also create additional stressors in the parents' lives.

The unpredictable behaviors of a child with ASD may cause parents to be hypervigilant in many social environments (Kuhlthau et al., 2014). Trying to navigate these high-stress social settings can cause parents to disconnect from other families, activities, and social opportunities. Many parents feel stigmatized because of the child's behavior issues and lack of interest in age-appropriate activities. The lack of social opportunities for families can make parents feel isolated. Research has shown there can be a significant relationship between the severity of ASD symptoms and higher levels of parental stress (Shamash & Hinman, 2020). Some co-occurring ASD characteristics that are linked to increased levels of stress are behavioral problems and difficulties in adaptive functioning and intellectual functioning (Mello et al., 2021). These high-stress levels can cause parents to be less effective in certain areas of the children's lives (Tomeny et al., 2016), impact the relationship between the parent and child, and increase mental health-related concerns for parents (Dimachkie Nunnally et al., 2023).

Parental stress can impact children's emotions and behaviors. Children with ASD may develop internalized or externalized behaviors from parental stress, even years later, when parenting stress is not as prevalent or impactful on behavior (Mello et al., 2021). Children with ASD may develop internalized behaviors such as anxiety and depression, while externalized behaviors like destructive or aggressive actions can be influenced by parental stress. A child's emotional difficulties and challenging behaviors can be influenced and even heightened by the parent's distress. Parental distress and a child's challenging behavior and emotions are mutually influencing (Mello et al., 2021). The distress can decrease a parent's sense of competence and limit their ability to implement parenting strategies and potential interventions.

Parent Mental Health-Concerns

The stress of caring for a child with ASD can lead to mental health-related problems for the parental caregivers. In a study of 52 parents caring for a child with ASD, 53.8% of parents showed clinically significant mental health problems (Dimachkie Nunnally et al., 2023). Many parents report feeling negative emotions due to the caregiver strain of raising a child with an ASD diagnosis. Some common emotions are anxiety, grief, sadness, depression, blame, and guilt arising from the emotional burden of caregiving (Marsack-Topolewski, 2020). In particular, guilt is a feeling that parents commonly experience (Kuhlthau et al., 2014). It can be directly related to the child with ASD by parents feeling they are not doing enough to support the child. Many parents have reported that they feel pressure to spend all of their free time helping the child with ASD and feel guilty if they engage in other activities. Parents can also experience guilt because they feel that they are not spending enough time with their other children without disabilities.

The mental health impact of having a child with ASD may impact parents differently. In one study, over one-third of mothers had higher rates of depression than mothers of typically developing children (Jones et al., 2017). In addition, mothers of children with ASD can have lower physical and psychological well-being than mothers of children with other disabilities like cerebral palsy or schizophrenia (Jones et al., 2017). Prolonged phases of grief and poor health status can also be faced by mothers when they have not entirely accepted their feelings about the child's diagnostic process (Myers et al., 2020). Mothers raising a child with ASD may encounter a more significant psychological burden than fathers (Dimachkie Nunnally et al., 2023) and face significantly higher levels of stress (Begum & Mamin, 2019). One research study shows that up to 70% of mothers feel high levels of distress resulting from raising a child with a severe disability, and only 40% of fathers feel high levels of distress (Begum & Mamin, 2019). Many studies on parental mental health in relation to a child's ASD diagnosis are conducted on the mothers as they are frequently the primary caregiver.

However, when a child is diagnosed with ASD, the mental health of both parents can be impacted. Fathers may be impacted differently than mothers. A father's satisfaction with his paternal role may affect his mental health (Rudelli et al., 2020). When a father feels a high level of self-efficacy as a parent to a child with ASD, this feeling can be associated with lower stress, depression, and anxiety. There is also research on fathers of a child with ASD suppressing emotions, which can cause feelings of anger (Begum & Mamin, 2019). Some research shows that a father's mental health may be impacted to a lesser degree than a mother's (Dimachkie Nunnally et al., 2023). However, when parenting a child with ASD, fathers can also feel symptoms similar to the mother, including anxiety and depression (Roig-Vila et al., 2020). Each parent may respond, experience, and cope with stress differently (Ardic, 2020).

Most parents worry about their children's future, but parents of a child with ASD frequently worry about their disabled child's future if they become sick or die (Aylaz et al., 2012). The concern can create significant stress and anxiety for parents. In research, Aylaz et al. (2012) interviewed parents raising a child with ASD and posed questions regarding death and caring for the disabled child. In the interviews, parents stated that a primary worry they have is who would care for the child with ASD if they were to die. Parents may have limited options when considering death and the care of the child with ASD. Parents hope the disabled child will be responsible and self-sufficient or that a reliable person will care for them when they are deceased (Aylaz et al., 2012). This type of stress may impact parents of children with severe disabilities like ASD and is not typically a concern for parents of typically developing children.

Parental Burnout and Financial Strain

Stress is a natural part of life, and parenting can elicit considerable levels of stress (Begum & Mamin, 2019). General parenting of a neurotypical child can cause stress for parents; however, with the addition of a disability, many parents experience significantly high stress levels. Specifically, parental burnout can be caused by chronic stress due to the developmental differences in a child with a disability and the level of care required for the child (Ardic, 2020). Children with ASD can have characteristics that are linked to increased parental burnout. Children with ASD may have behavioral concerns like dysregulation, externalizing behaviors, and restricted and repetitive behaviors, which are difficult for parents to manage (Dimachkie Nunnally et al., 2023). These characteristics may lead to increased caregiver strain.

The care for a child with ASD can be continuous and typically a life-long commitment for parents (Marsack-Topolewski, 2020). Parents may be responsible for the ongoing care of the child with ASD and the needs of the family. The constant care for family and the needs of the child with ASD can be compounded by poor social support; parents may experience decreased motivation and energy, which may result in parental burnout (Ardic, 2020). Parents may also be challenged to fulfill the long-term care necessary for the child with ASD, ensure services are accessible to the child, accept the economic costs of education and therapy, and oftentimes sacrifice a social life. This can lead to further parental burnout (Ardic, 2020).

Raising a child with a disability can impact a parent’s psychological well-being, marital satisfaction, and mental and physical health; however, another impact is the financial aspect of disability (Kuhlthau et al., 2014). In addition to the parents' commitment to caring for the child with ASD long-term, they may also experience significant financial strain from expenses relating to the child's ASD disability (Begum & Mamin, 2019). Some of these expenses are related to paying for doctor's appointments and the child's therapeutic support, like speech-language therapy, occupational therapy, and behavioral therapy (Kuhlthau et al., 2014). Additional expenses can arise indirectly when one parent decides to sacrifice their career to become the child's full-time caregiver. Researchers found that 24% of parents raising a child with a disability had to reduce their work hours or stop working altogether due to the child's medical care (Zablotsky et al., 2014). Employment struggles or loss of employment can influence the care provided to the child with ASD. Employment concerns can lead to lower family income and potentially less insurance coverage (Kuhlthau et al., 2014). Some insurance plans do not cover costs associated with ASD (Zablotsky et al., 2014). In fact, 36% of private healthcare plans exclude ASD, which can mean higher costs and delayed services for families paying out of pocket.

Research has documented a possible link between parental income and their satisfaction with the child’s diagnostic process, special education eligibility, and pediatric support (Hidalgo et al., 2015). Specifically, parents with higher incomes may be more satisfied with the child’s special education eligibility process and with the care the child receives from a pediatrician.

Families with lower household incomes may not be as satisfied in these areas and appear to have more barriers to accessing these services than families with higher incomes. Therefore, socioeconomic factors like parental income may influence the services and support available for children with ASD and can affect parental satisfaction.

Marital and Relationship Satisfaction

Parents who care for a child with ASD may face unique challenges that can impact a marital relationship. They often have to balance the time between raising typically developing children and time together as partners when they have the additional pressure and strain of raising a child with a disability (Brobst et al., 2009). The parents of a child with ASD may have more barriers placed on the relationship, like high-stress levels, behavior challenges from the child with ASD, and lower social support compared to parents raising children without a developmental disability. These challenges for the parents navigating ASD can lead to lower relationship satisfaction.

As spousal partners in a relationship, it’s important for parents to support each other. Brobst et al. (2009) discuss that when a child with ASD has more severe behavior problems, marital support, respect, and commitment may be strained. This can be due to the father becoming less supportive of the mother when problematic behavior arises from the afflicted child. A significant link may exist between spousal respect and appreciation when parenting a child with ASD. It may be necessary to have a supportive spousal relationship to provide emotional comfort and discuss feelings regarding caregiver duties and resolve conflict together (Easler et al., 2022). Having positive marital quality may help lower stress more than social support, child characteristics, or socioeconomic status.

Having a child with ASD can adversely impact the routines of family life and marital relations (Aylaz et al., 2012). A couple's sexual well-being may be impacted by the diagnosis of a child with ASD. Studies have shown that the birth of a child with a disability may cause stress and a decreased sexual drive in couples. Although the sexual decline and stress may begin with the child's birth, it does not subside as the child ages. Aylaz et al. (2012) state that parents can have frustration, guilt, low matrimonial satisfaction, and impaired sexual lives because of feelings of inadequacy from raising a child with a disability. This can be especially true for mothers who tend to be the primary caregiver for a child with ASD. Mothers may experience a more adversely impacted sexual life because of the fatigue, guilt, and care they experience parenting a child with ASD. The lack of sexual relations between a married couple due to the demands of caring for a child with ASD can impact the mother's self-confidence and mental health, which can cause further marital discord and potentially lead to divorce.

Divorce can be a traumatic childhood event that can be caused by lower marital satisfaction and higher levels of mental-health issues (Bahri et al., 2023). The high levels of stress and the demands placed on parents; additionally, caring for children, time constraints, and behavior challenges, can impact the parent's mental health and relationships. Parents of children with ASD may be at a moderately increased risk of experiencing divorce in comparison to parents raising a child without a disability. The risk of divorce can change throughout the child's development. Bahri et al. (2023) found that the two highest-risk developmental phases for divorce may be when the child is zero-five years of age and older than 15. The other factors that may influence divorce risk are parents with less than a college education and mothers who were young when the child was born. In addition, parents who only have one child with ASD may have a higher risk of divorce in comparison to parents that also have typically developing children.

The Impact of Autism Spectrum Disorder on Siblings

Many children with ASD grow up with a sibling. Siblings can have strong emotional ties that are almost as emotionally significant as the parent and child relationship (Furman & Buhrmester, 1985, as cited in Rivers and Stoneman, 2003). It is common for typically developing siblings to have a positive impact on a sibling with ASD. They can model skills in deficit areas for the child with ASD, like social interactions and language, appropriate behaviors, and new competencies (Guidotti et al., 2020). However, children with ASD can adversely impact the typically developing siblings. Children with ASD may have characteristics that impact interactions with others, like social and communication deficits (Rivers & Stoneman, 2003). These qualities may impact a sibling relationship. Besides ASD characteristics, there are other factors that influence the relationship between a child with ASD and the typically developing sibling. Research has shown that other elements like age, gender, and birth order may influence the relationship between the child with ASD and siblings (Guidotti et al., 2020; Koukouriki, Athanasopoulou, & Andreoulakis, 2021), as well as marital stress and discord (Rivers & Stoneman, 2003).

On the other hand, research also documents positive impacts for typically developing siblings via their relationship with the sibling with ASD. Compassion, acceptance, and empathy can result from the challenges of having a sibling with ASD (Iannuzzi et al., 2021). The combination of positive and negative implications between a typically developing sibling and the brother or sister with ASD is similar to the relationship between neurotypical siblings, where positive and negative experiences may occur together (Laghi et al., 2023).

Marital Discord and Parental Stress on Sibling Relationships

Marital quality can be adversely impacted by children with ASD due to increased parental stress (Tomeny et al., 2016). Poor marital quality can affect the typically developing children in the family. The conflict between parents may be associated with decreased adjustment in neurotypical children. Tomeny et al. (2016) suggest that typically developing children are usually more aware of a parent's emotional state and may notice the dissatisfaction with the parent's marriage better than the sibling with ASD. When parenting stress from raising a child with ASD causes marriage dissatisfaction, siblings of children with ASD can also develop behavior problems (Rivers & Stoneman, 2003). These behavior challenges can impact the relationship between the child with ASD and the siblings. When a marriage is experiencing high stress levels, typically developing siblings may experience more negative behaviors and can direct less positive behaviors toward the sibling with a disability. This response can be due to the siblings' emotional reaction to the parents' marital stress. Many children are significantly impacted if marital discord results in parental separation (Tomeny et al., 2016). Children who experience divorce may have worse academic achievement, self-concept, and peer relationships.

The stress parents may face when raising a child on the autism spectrum can have ripple effects on the typically developing children. Parents managing stress from raising a child with ASD may be less able to manage emotions and show appropriate behaviors toward the typically developing children (Tomeny et al., 2016). This stress can have negative implications and make parents less effective in the parental role. Less effective parenting may have repercussions on the siblings of a child with ASD. Parental stress can have additional consequences on typically developing children, such as hindered social abilities and behavioral challenges.

Symptoms and Severity of Symptoms on Sibling Relationships

The symptoms and characteristics of a child with ASD can directly impact sibling relationships. The severity of the symptoms, nature of the behavior problems, and presence of other comorbid conditions can intensify the impact on the typically developing siblings and the sibling relationship (Rixon et al., 2021). A significant factor that may impact a sibling relationship is challenging behavior. Children with ASD with challenging behavior problems are more likely to have a more adverse sibling relationship (Rixon et al., 2021). Additionally, research has shown that children with ASD with more severe symptoms can cause more emotional and behavioral problems in typically developing siblings (Iannuzzi et al., 2021; Tomeny et al., 2016).

The problematic behaviors exhibited by some children with ASD can cause stress and concern for families (Rochefort et al., 2023). Challenging behaviors can vary in frequency and severity for each child with ASD. These behaviors can come in many forms, such as hitting and biting. Some siblings of children with ASD are frequently exposed to and suffer from challenging behaviors, directly or indirectly. This repeated exposure to challenging behaviors may cause trauma for the typically developing siblings that grow up in the same environment as a child with ASD (Rochefort et al., 2023). Developmental trauma theory suggests that "trauma can occur from being repeatedly exposed to severe stressors (e.g., emotional, physical, sexual, neglect, and witnessing violence) during childhood or adolescence within significant relationships which are typically expected to be the source of security, protection, and stability" (Rochefort et al., 2023 para. 6). With this understanding of developmental trauma theory, siblings of children with ASD may experience situations consistent with the defining features of this concept, which may have significant impacts on a typically developing sibling’s well-being.

Sibling relationships can be more positive when children with ASD have less severe behavior challenges and adjustment difficulties (Iannuzzi et al., 2021). However, research is inconsistent on this topic, as sibling relationships comprise positive and negative experiences (Laghi et al., 2023). Iannuzzi et al. (2021) concluded from a study that some typically developing siblings felt more supportive, empathetic, and protective of the brother or sister with more severe ASD symptoms. Additionally, some children with less severe ASD symptoms were more problematic to sibling relationships. The ASD sibling relationship can be described differently in each family (Rivers & Stoneman, 2003).

Birth Order, Age and Gender On Sibling Relationships

Birth order can be a factor in personality development and behavioral characteristics (Koukouriki, Athanasopoulou, & Andreoulakis, 2021). Some positive factors may exist to being a firstborn sibling in a family, such as better academic performance in school. Additionally, first born children who have a sibling with ASD can also have better social functioning and satisfaction than other siblings in the family. Siblings younger than the first-born child may have more adverse impacts when there is a child with ASD in the family, such as feelings of loneliness and social dissatisfaction. Siblings younger than the child with ASD potentially have less time with parents due to the needs of the sibling with ASD, which can impact the younger child's growth and development.

In addition to birth order, the age of the children in a family can also impact sibling relationships. Laghi et al. (2018) studied children in three age groups: early adolescents, middle adolescents, and young adults. The youngest group, early adolescents, was the most adversely impacted by having an ASD sibling. This group engaged in the most negative behaviors with the ASD sibling compared to the other two age groups. A potential reason for this finding is that children in early adolescence may spend more time with siblings. In contrast, the older age groups have more friendships and relationships outside of family. Laghi et al. (2018) state that increased conflict can occur when younger siblings spend more time together, especially in early adolescence. The early adolescent age group also may have a more challenging time navigating the symptoms from the ASD sibling than the middle adolescent and young adult age groups. The older age groups, the middle adolescent and young adult groups, may have developed more effective coping mechanisms to deal with the ASD siblings' behaviors and symptoms.

Gender can be a factor in the quality of the relationships between typically developing siblings and siblings with ASD. Females, in comparison to males, may have a more positive relationship with a sibling with ASD (Guidotti et al., 2020). Males and females typically have different relationship styles because of gender differences. Males may engage in more argumentative behavior and conflict, whereas females may take on more of a caring and nurturing role for the ASD sibling. Unlike males, females often disengage from conflict and try to maintain an affectionate and loving relationship. Females may also take on more of a long-term caregiver role for the sibling with ASD (Tomeny et al., 2016). The difference in the relationship between males and females with the sibling with ASD is most likely due to societal pressures for females to care for the family.

Parentification on Sibling Relationships

The care typically developing siblings provide the child with ASD can be termed parentification in research (Guidotti et al., 2020; Koukouriki, Athanasopoulou, & Andreoulakis, 2021). Parentification may lead to a more positive connection between siblings (Guidotti et al., 2020) or adversely affect the typically developing sibling (Rochefort et al., 2023). Siblings who take on more responsibilities for the sibling with ASD may struggle to develop relationships with peers. This may be due to the maturity level of the typically developing sibling exceeding their developmental age. Having responsibilities and a maturity level beyond a developmental age may cause challenges for children looking to build peer relationships. Some of the roles and responsibilities that siblings may take on can be watching the sibling with ASD so they do not engage in self-injurious behaviors (Koukouriki, Athanasopoulou, & Andreoulakis, 2021; Rochefort et al., 2023) or completing household duties to support the family (Koukouriki, Athanasopoulou, & Andreoulakis, 2021). Siblings who experience high levels of parentification, especially when it is more focused on the caregiving of the parents, are more likely to experience distress, anxiety, and depression as adults (Laghi et al., 2023).

Caring for an individual with ASD may be a responsibility for a typical developing sibling in adulthood. Many siblings worry about the care an ASD sibling requires with age and are concerned that the caregiving burden will be their responsibility in the future (Iannuzzi et al., 2021). As parents age and become less fit to be the caregiver to the child with ASD, this becomes more of a reality for siblings. Even if the typically developing siblings do not take on the role of the primary caregiver for the child with ASD, typically developing siblings may need to provide support with financial management.

The Effect of the Sibling Relationship on Other Relationships

Having a sibling with ASD can impact other peer relationships for the typically developing siblings, including both positive and negative impacts (Schmeer et al., 2021). Some siblings describe the influence of the sibling with ASD as positively impacting social relationships by helping them determine who to be friends with based on their peers' acceptance of individuals with disabilities. Additionally, some siblings may feel more willing to interact with and stand up for other individuals with disabilities because of the influence of the sibling with ASD (Iannuzzi et al., 2022).

However, typically developing siblings sometimes feel they must navigate between being socially accepted by peers and being loyal to the sibling with ASD (Schmeer et al., 2021). This can be difficult because siblings may feel embarrassed by the ASD sibling's unpredictable behaviors in a public setting or in the home environment which can lead to increased hypervigilance and anxiety (Iannuzzi et al., 2022). This feeling of embarrassment may prevent typically developing siblings from going out in public with the sibling with ASD (Iannuzzi et al., 2022) or inviting friends over (Schmeer et al., 2021). Some siblings fear being judged because of the sibling's behaviors and find it challenging to discuss the sibling's diagnosis with people outside of the family (Iannuzzi et al., 2021).

Some typically developing siblings may be unwilling to share information about the sibling's disability because they worry other people would not understand the ASD diagnosis (Petalas et al., 2009), be interested in hearing about it, or be able to relate to it (Iannuzzi et al., 2022). Typically developing siblings may feel it is difficult to navigate friendships. Feeling reluctant to share information can be isolating for typically developing siblings who are navigating the diagnosis of a sister or brother. Research has found that siblings of children with ASD are typically more lonely than neurotypical siblings or siblings of children with intellectual disabilities (Petalas et al., 2009). In addition, some typically developing siblings feel that peers are not accepting of individuals with disabilities or are unaware of how to behave around individuals with disabilities (Petalas et al., 2009). Typically developing siblings may need a support system to share feelings and discuss the brother or sister's ASD diagnosis openly and with individuals that will not discriminate or show prejudice.

ASD is a unique disorder as it can have invisible symptoms. Some individuals with ASD can behave typically and have no physical signs of disability (Moyson & Roeyers, 2011). Having no physical features or characteristics of the disorder can cause people to assume that the diagnosis does not exist. These invisible symptoms can impact the typical sibling's relationships with peers. Peers of typically developing siblings may not recognize the child with ASD as being disabled. According to Moyson & Roeyers (2011), some individuals with ASD who have invisible symptoms may appear neurotypical. People may view ASD behaviors as an annoyance when they are not informed of the diagnosis. There can be disadvantages to invisible symptoms. Some might assume that the child's behavior challenges are due to poor parenting without understanding the ASD diagnosis. Knowing the ASD diagnosis can help people be more accepting of the characteristics and symptoms. Additionally, if the sibling with ASD does not exhibit obvious ASD features, typically developing siblings may have to “prove” (Moyson & Roeyers, 2011, p. 51) to others and explain the siblings' diagnosis, even if they are uncomfortable doing so.

Sibling Mental-Health Concerns

The mental health impact of a sibling with ASD on typically developing siblings is essential to understand and address. Siblings of individuals with ASD may be at a higher risk for mental health problems (Shtayermman & Fletcher, 2022), including depression and anxiety (Jones et al., 2020). These mental health impacts may be due to the stress caused by the disorder or the aggression that a typically developing sibling can be directly or indirectly victim to from the sibling with ASD. Some research shows a connection between ASD symptoms, challenging behaviors, and mental health. These mental health impacts of diagnosis can also be gender specific. Sisters can be more at risk of emotional and behavioral challenges (Tomeny et al., 2016), maladaptation when the sibling has severe ASD symptoms, and more significant mental health challenges (Jones et al., 2020). This may be due to females taking on more responsibilities and a caregiver role for the sibling with ASD. Other factors like birth order, sibling developmental level, parental stress, and family income can impact sibling mental health.

Genetic components can also be linked to mental health issues for some typically developing siblings. Some siblings of individuals with ASD may exhibit ASD characteristics but not meet the full criteria for an ASD diagnosis (Kurtz et al., 2023). Individuals who have ASD tendencies but do not meet the ASD criteria can be considered to have broad autism phenotype (BAP) traits (Koukouriki, Soulis, & Andreoulakis, 2021). BAP traits are genetically based and found in family members of an individual diagnosed with ASD. These traits can be similar to those listed in the criteria for an ASD diagnosis, like communication difficulties, stereotyped behaviors, difficulties recognizing emotions, and being less skilled socially (Kurtz et al., 2023).

Siblings who have BAP may have an increased risk for psychological disorders and cognitive impairments (Kurtz et al., 2023). Additionally, they may have higher rates of obsessive-compulsive disorder, anxiety, and mood disorders. According to Kurtz et al. (2023), if a BAP sibling has more symptoms associated with ASD, they may be more likely to experience increased depression and anxiety symptoms in comparison to a BAP sibling with fewer ASD traits.

The typically developing siblings of children with ASD can have a lifelong struggle with mental health. Mental health issues can begin if the typically developing sibling internalizes feelings of depression and anxiety (Shtayermman & Fletcher, 2022). These feelings can continue into adulthood if typically developing siblings are required to support or care for the sibling with ASD. Typically developing siblings may be twice as likely to receive a depression diagnosis in young adulthood in comparison to the general population (Koukouriki, Soulis, & Andreoulakis, 2021). The mental health struggle for typically developing siblings can be ongoing and may lead to an increased risk of suicide attempts (Shtayermman & Fletcher, 2022). Data shows that males may be at higher risk than females for suicide. For older typically developing siblings, anxiety can escalate and lead to thoughts of suicide. This can be because of the unpredictability of living with a person with ASD and the potential of being a caregiver as parents age.

Supports for Families with a Child with Autism Spectrum Disorder

Some areas of research support that when a child is diagnosed with ASD, the functioning of a family declines; however functioning can be malleable and can be supported with interventions (Brockberg & Smedema, 2022). Parents often search for support to help them cope because of the stressors involved in raising a child with ASD (Shepherd et al., 2020). Support and interventions can be provided to help families. When a child is diagnosed with ASD, most family members are impacted. However, it is not sufficient to just provide parents and families any supports (Balcells-Balcells et al., 2019). It is important to identify the support the family requires to ensure the deficit areas in the family are being reduced, and the quality of life is improved for the family as a whole. The supports must match the area of difficulty in a family. When one individual struggles in a family because they are not receiving the support they need, the whole family can suffer because they influence each other (Koukouriki, Athanasopoulou, & Andreoulakis, 2021). Supports and interventions for families are critical factors in the quality of life for the parents, siblings, and the child with ASD. However, supports, services, and resources can be inaccessible to families or challenging to locate and access (Avery et al., 2022). Parents who have a child with ASD typically have less support than parents of neurotypical children (Avery et al., 2022).

It is essential to approach support and intervention from a family perspective and ensure that all family members receive the formal, and informal support they require (Balcells-Balcells et al., 2019). Interventions directed toward the child with ASD should also be intended to improve the whole family's well-being (Leadbitter et al., 2018). Parents can be impacted if support and services are not family-centered because they cannot balance all the family responsibilities (Avery et al., 2022). Some services that may support the entire family's well-being include respite care, family counseling, therapeutic services, and parent learning sessions (McConkey et al., 2020).

Engaging in Self-Care

Parents of children with ASD often manage many responsibilities for a family, especially for the child with ASD. Some parents manage the education, health care, and therapeutic services for the child with ASD (Avery et al., 2022) and other roles. The multiple roles the parents take on can overlap. Parents often take on many responsibilities within the home and outside of the home. These can include organization, advocacy, education, and caregiving (Avery et al., 2022). It can be challenging for parents to balance responsibilities between work, home, and community.

Having these multiple roles may limit a parent's time for self-care. It is common for parents of children with disabilities to spend more time on the needs of the children than on their own needs (Gilson et al., 2017). Engaging in self-care can help improve the well-being of parents. Gilson et al. (2017) suggest that some activities to promote parental well-being include exercise, seeing friends, volunteering, or finding activities that interest the parents and provide a sense of happiness to them. However, some barriers can also prevent parents from looking after themselves. Limited access to support, worries about the future, poor acceptance from the community, changes in income, and insufficient time can all impact the parents' opportunities for better well-being (Gilson et al., 2017).

Knowledge for Families

For many families navigating an ASD diagnosis, the highest priority is obtaining knowledge about the illness (Balcells-Balcells et al., 2019). However, many families struggle to receive accurate information from professional supports (Magalhães & Pereira, 2017) and therefore seek alternative sources of information, often via the Internet. The Internet is a commonly used informal source of support for parents to get information about ASD, but the quality of information parents receive can be a disadvantage of using this source. According to Magalhães & Pereira (2017), some parents may be unable to discern validity of information, which may pose a risk to them and only exacerbate their questions and concerns about the diagnosis. The Internet can adversely affect the parents' perspective and understanding of an ASD diagnosis (Magalhães & Pereira, 2017). These adverse effects can impact the child, parents, and family in the present and the future.

When families know more about the ASD diagnosis, the knowledge they gather can empower them to advocate for the child with ASD, be more confident, understand the disorder, and have more control (Searing et al., 2015). Shepherd et al. (2020) state there may be a connection between accessing formal sources for information and better parental psychological health due to the development of better parenting competencies. Knowledge of the disability and having experience supporting a child with ASD also help parents share lived experiences and knowledge with other parents looking for support (Searing et al., 2015). Knowledge is essential for parents as it can help children with ASD and families obtain proper support and services (McConkey et al., 2020). Parents also need to be willing to obtain information on an ongoing basis as family needs will change over time, and they may have to alter family supports and services. It’s important that parents are able to access accurate information easily. Passive materials like brochures can be effective ways to communicate information and education to parents (Gilson et al., 2017). Parents can also seek out information from healthcare professionals, ASD organizations, and even other families that have experience raising a child with ASD.

Types of Supports

The support that families obtain can be from different sources, and they may fulfill different needs of the family (Searing et al., 2015). Social support can be accessed informally or formally (Searing et al., 2015) and in a variety of environments. High levels of social support can lower levels of stress and depression in parents of children with ASD and increase the parent’s emotional and physical well-being. Social support may significantly improve a family’s ability to adapt, cope and have family cohesion (Lei & Kantar, 2022). Many families who have a child with ASD begin to obtain supports and services when the child is around the age of 3 (Garbacz et al., 2016), and services may continue throughout the child's years in school. Supports and services may be provided to an individual with ASD and to the family for the individual's entire life.

Informal support can come from the family’s social networks, such as extended family, neighbors, or friends (Searing et al., 2020; Shepherd et al., 2020). These types of support are not formal support or service agencies (Shepherd et al., 2020). The individuals who provide this support do so on a casual basis and with no fee associated with it. This type of support can be essential to families because it is often a significant source of emotional support for parents raising a child with ASD. It is also considered the preferred method of support to parents as it provides "greater flexibility and a more 'human touch' than the 'mass-production-one-size-fits-all' solution typically offered by formal support organizations" (Shepherd et al., 2020, p. 4339). With this informal support, parents may experience increased face-to-face interactions within their peer networks, fostering a sense of qualified and genuine support. Informal support can also be more flexible than formal support because formal support requires booking a timeslot in advance (Shepherd et al., 2020).

Formal supports can also be provided to families who are looking for help raising a child with ASD. Formal supports are usually not volunteer-based like most informal supports (Shepherd et al., 2020). Typically, these paid supports are provided to families by individuals in a professional organization (Searing et al., 2020). Examples of formal supports and services are family doctors, private therapy, respite services, intervention services, and autism organizations (Shepherd et al., 2020). Formal supports are appealing to parents when they wish to seek out professional guidance and information regarding a child's ASD diagnosis (Searing et al., 2020).

Examples of Informal Supports for Families

Family members can be an informal source of social support, often including grandparents (Searing et al., 2015). Having close family members provide support can be considered extremely valuable to parents. However, some families report that, at times, the support from family can be less helpful due to differences in perspectives of the ASD diagnosis and parenting styles among family members, such as grandparents and the parent of the child with ASD.

An individual's spouse can also be a helpful source of informal support (Hall & Graff, 2011). Spousal support is often the first source of social support to protect the family from adversity related to an ASD diagnosis (Avery et al., 2022). The spouse's role as a primary social support is most likely because parents would rather discuss private family matters among themselves rather than with unfamiliar individuals. However, relying heavily on spousal support can result in both parents suffering because of high stress levels. In addition, when one spouse is frequently or permanently absent from the family's lives, stress levels can increase (Hall & Graff, 2011). This can be a disadvantage of relying on family members for support. Family members can often be unavailable (Searing et al., 2015) to provide assistance when needed, which can have a significant impact if they are the family's only source of social support. It’s important for family members to have multiple forms of support. It is also imperative to find additional supports as children with ASD grow older because some families express that family support decreases as the child with ASD ages (Hall & Graff, 2011).

Parents may also seek peer support groups as an informal source of support. Parents can receive emotional support and engagement with other families who also have a child with ASD in such groups (Gilson et al., 2017). Finding others with similar family situations can be beneficial for families looking to find others to talk to. However, some parents may isolate themselves at these social gatherings, especially if they perceive the support does not benefit them or the family (Hall & Graff, 2011).

Social support can also be beneficial to siblings of children with ASD. It can positively influence a sibling’s life which can help balance the negative impact of living with a sibling with ASD (Garrido et al., 2020). According to Garrido et al. (2020) social support may help siblings achieve better adaptive adjustment and quality of life. Higher levels of social support may result in more positive results. A consistent form of social support can improve the siblings' quality of life and the overall satisfaction of the entire family.

The need for informal supports is ongoing because the child with ASD will most likely require some degree of care from their parents throughout adulthood (Marsack & Hopp, 2019).

When children with ASD become adults, families still require supports. Each adult with ASD may have differing cognitive abilities, social skills, independent living capabilities, and comorbidities (Anderson & Butt, 2018); therefore, many parents will still be accountable for their child's well-being, access to activities and coordinate their child's supports and services. Informal supports continue to be helpful for parents of adults with ASD to discuss their concerns with other parents with children with similar needs (Marsack & Hopp, 2019). Living with an adult with ASD may present different support challenges as parents age and potentially face physical health limitations. Aging parents may even need caregiving assistance from informal supports if they experience a decline in physical health (Marsack & Hopp, 2019). Informal support sources will continue to benefit families and parents of adult children with ASD.

Examples of Formal Supports and Services for Families

Formal supports for families who have a child with ASD come from professionals who provide information, assistance, and guidance (Searing et al., 2015). These supports may come at a monetary cost and are either privately or publicly funded. Like with informal support, the intention behind formal support is to lower family stress and improve the quality of life for the family as a whole. However, just like with informal support, some families struggle to access the formal professional supports and services they desire.

A child's family doctor can be one of the first formal supports a family seeks when they perceive a child has a disability. They are the person who typically guides a family through the diagnostic process by assisting with finding specialists and appropriate interventions for the child with ASD (Searing et al., 2015). However, some families feel that the child's doctor is not a helpful source of family support. Searing et al. (2015) show that 54% of families view the child's family doctor as not being very effective in meeting the family's needs. If this finding is replicated, it is possible that some professionals could learn more about the family experience of raising a child with ASD so they can be supportive, helpful, and empathic.

Respite is a formal support that can be provided to families who have children with disabilities. Respite relieves parents of parental responsibilities for a short time while a professional cares for the child with ASD (Gilson et al., 2017). Respite can provide parents a short-term break inside or outside of the home environment. Having this break from the child with ASD can also support parental wellbeing. However, Gilson et al. (2023) state that some parents report barriers to receiving respite. The quality of care the child receives when the parents are away is a concern for some families. Parents may also feel a sense of guilt that they are trusting another individual to care for the child with ASD without knowing this individual previously or having any relationship with them.

Early childhood intervention can be considered one of the most effective ways of treating ASD symptoms in children and improving child development (Bharat et al., 2022). Early childhood intervention has "the possibility of preventing the most serious and complete manifestations of ASD by making use of the plasticity of the brain in the early stages" (Magalhães & Pereira, 2017, p. 248). This intervention is a formal source of support and services for families to support young children with disabilities in acquiring critical developmental and learning skills (Bharat et al., 2022). Some areas worked on in early childhood intervention include social and emotional, behavior, communication, and physical and cognitive skills. This form of intervention is aimed at a preschool aged child with ASD but has benefits for the whole family (Leadbitter et al., 2017). Early childhood intervention can support the well-being and quality of life of the parents, siblings, and child with ASD.

Additionally, early childhood intervention can have long-term benefits even years after treatment is complete (Leadbitter et al., 2017). The intervention can have lasting benefits on the parents' confidence, self-efficacy and ability to cope. Many parents value early childhood intervention for its support for children with disabilities and its effect on the family (Avery et al., 2022).

However, parental satisfaction with early childhood intervention is also inconsistent. Searing et al. (2015) reports that the satisfaction rating by some parents in a study on early childhood intervention programs can be low. Some parents raise concerns over the early childhood intervention program and its lack of focus on the priorities and concerns of the parents (Magalhães & Pereira, 2017). Additionally, some parents feel that the child with ASD needs more intensive intervention than is provided. They may feel that the frequency of the sessions, the timeframe, and the number of sessions provided are insufficient to support the child's development.

Counseling is a formal support resource that can be available to families with children with ASD. It can provide parents and families with additional emotional support (Gilson et al., 2017) as families navigate the stress and challenges of an ASD diagnosis. Families can participate in different types of counseling therapy, like relationship (Gilson et al., 2017) or family counseling (Solomon & Chung, 2012). Therapists frequently provide valuable support to parents experiencing acute or chronic stress levels while raising a child with ASD (Solomon & Chung, 2012). They can also assist spouses when a marital relationship is strained and are worried about the potential risk of divorce. Parents who have typically developing children in addition to a child with ASD can also see a therapist to find support in balancing the needs of all the children and maintaining a close relationship.

Families often provide inconsistent feedback regarding counseling as a formal support source. Accessing counseling can be difficult for some families. Some parents feel that finding a suitable counselor to support family needs is difficult (Gilson et al., 2017). In order to be effective, the counselor should be knowledgeable of the ASD diagnosis, understand what type of therapy is best for the individuals, and have a certain level of care for the family living with the impact of ASD. The cost of therapy can also be problematic if families are responsible for covering the fees associated with the counseling sessions, and many families may have time barriers that prevent them from attending therapy (Gilson et al., 2017).

After school care for children is a formal support that some families use. Parents who work outside the home often place children in quality after school care. For parents of a child with ASD, there can be intense daily demands that may be unimaginable to individuals who are inexperienced in parenting children with disabilities (Haney, 2011). These multiple roles may cause additional stress to already overwhelmed parents. Parents of children with ASD want high quality afterschool programs to provide care. After school child care programs may benefit many children as they provide opportunities for socialization and building relationships. After school childcare programs can provide benefits for children with ASD as well as typically developing children. Most often, children with ASD have fewer relationships with peers; instead, their social circle may be limited to their parents, siblings, and the individuals that provide them with supports and services (Haney, 2011). After school programs can provide children with ASD opportunities to practice socialization with more peers and work on generalizing some skills learned in school and therapy in a new environment.

For some parents raising a child who is diagnosed with ASD, finding quality childcare can be difficult. After school care options may be limited for parents. Some children diagnosed with ASD can exhibit challenging behaviors and different communication methods; they may have more significant supervision needs (Haney, 2011). Some private daycares may exclude children who exhibit these characteristics. After school childcare facilities may also be overcrowded and have too much stimulation for some children. In addition, it can be challenging to find after school childcare facilities that have the training to work with children with ASD. After-school care programs can benefit families with children with ASD, but finding the right provider to meet the individual child and family needs can be difficult.

CHAPTER III: DISCUSSION AND CONCLUSION

Summary of Literature

Autism Spectrum Disorder (ASD) is a neurodevelopmental disability that impacts many families (CDC, 2023b). As the prevalence of ASD increases, more families may require support coping with the adverse impacts it can have on a family. Families are often interconnected, with intense interactions and reactions to the environment according to family values (Koukouriki, Athanasopoulou, & Andreoulakis, 2021). With this interconnection, when one family member is impacted, it spreads through the entire family (Minuchin, 1985, as cited in Koukouriki, Athanasopoulou, & Andreoulakis, 2021). A child diagnosed with ASD can significantly affect the functioning of a family.

Although an ASD diagnosis may impact most family members, parents can be impacted differently than the siblings of children with ASD. Parents typically manage the responsibilities for the child's personal care, socialization, and well-being; then, additionally coordinate health care and educational professionals (Tongerloo et al., 2015). As caregivers of a child with ASD, parents may have increased stress and financial strain and decreased physical and mental-health wellness (ten Hoopen et al., 2019). The effects of ASD on parents can manifest even before the formal diagnosis is made. Parents can feel helpless and frustrated as they painfully wait an extended time to receive an official diagnosis for the symptomatic child (Roig-Vila et al., 2020). Once the child is diagnosed, parental stress is not necessarily alleviated. Parents may have to manage the child's unique and often challenging ASD characteristics. These characteristics, especially challenging behaviors, can cause parents to disconnect from other families, activities, and social opportunities because of the stigma, stress, and hypervigilance of being in a public realm (Kuhlthau et al., 2014). The high-stress level from raising a child with ASD can also increase negative perceptions and lower self-efficacy in parents (Shamash & Hinman, 2020).

Some parents may feel negative emotions like grief, sadness, anxiety, or depression from the child's experience of ASD (Marsack-Topolewski, 2020). They may also feel guilt from perceiving that they are torn between caring for the child with ASD and spending time with typically developing children (Kuhlthau et al., 2014). The mental health impact may also differ between a mother and a father. As mothers may take on a more primary role in raising the child with ASD, they may feel higher levels of distress than fathers of children with ASD (Begum & Mamin, 2019).

Caring for a child with ASD may be a lifelong responsibility; therefore, the stress does not dissipate with age. Parents may worry about the child with ASD in the future and what will happen to the child if they become sick or deceased (Aylaz et al., 2012). The concern for the child's future can cause significant stress and anxiety for parents. The continuous care and high-stress levels required for raising a child with ASD may lead to parental burnout (Ardic, 2020).

The financial strain of disability may impact parents. There may be monetary costs for medical expenses related to the child's disability, doctor's appointment fees, or costs associated with therapy (Kuhlthau et al., 2014). Parental finances can also be impacted if a parent has to have reduced work hours or stop working to care for the child with ASD (Zablotsky et al., 2014). This can reduce household income and the parent's insurance coverage (Kuhlthau et al., 2014). Parent income may also factor in the feeling of satisfaction with the child's diagnosis and the support parents receive for the child (Hidalgo et al., 2015). Higher parental income may be correlated with more satisfaction with the child's special education process and the care the child receives from a doctor.

Parents with typically developing children and a child with ASD must balance making time for the needs of the children and relationship needs (Brobst et al., 2009). Some barriers parents face when raising a child with ASD are high-stress levels, behavior challenges, and limited social support. These barriers may lead to lower relationship satisfaction. In addition, the demands of caring for a child with ASD and parental feelings of inadequacy can cause an impaired sexual relationship between a married couple (Aylaz et al., 2012). Lower marital satisfaction and more significant mental health issues can lead to divorce (Bahri et al., 2023). Parents of children with ASD may have a moderately increased risk of experiencing divorce in comparison to parents raising a child without a disability.

The experience of ASD can have both positive and negative impacts on siblings of children with ASD. Marital discord can adversely impact typically developing children and cause them to have a poor adjustment in life (Tomeny et al., 2016) and develop challenging behaviors (Rivers & Stoneman, 2003). If divorce occurs, children may experience worse academic achievement, self-concept, and peer relationships (Tomeny et al., 2016). The impact of stress on parents may diminish their effectiveness in parenting, potentially resulting in consequences for their neurotypical children, such as delayed social abilities and behavioral problems.

The severity of ASD symptoms a child has may impact sibling relationships. Children with more severe behavioral challenges are likelier to have adverse sibling relationships (Rixon et al., 2021). Challenging behaviors may lead to trauma for typically developing children if they have repeated exposure to and suffer from the sibling’s challenging behavior (Rochefort et al., 2023). However, research is inconsistent on the impact of ASD severity on sibling relationships.

Sibling relationships can also be positive, including when children with ASD have severe symptoms (Iannuzzi et al., 2021).

Birth order, age, and gender can impact the relationship a child with ASD has with the neurotypical sibling. Being the first-born child in a family with a child with ASD is associated with better social functioning and satisfaction than the other siblings (Koukouriki, Athanasopoulou, & Andreoulakis, 2021). Other siblings are more likely to experience loneliness and social dissatisfaction. Children in an early adolescent age group are more likely to be adversely affected by having a sibling with ASD and develop negative behaviors in comparison to the middle adolescent and young adult age groups (Laghi et al., 2018). Gender may also affect the quality of relationships typically developing siblings have with the sibling with ASD. Males may argue more, whereas females can be more caring and nurturing (Guidotti et al., 2020). Young females may also take on the caregiving role for the sibling with ASD, called parentification (Guidotti et al., 2020; Koukouriki, Athanasopoulou, & Andreoulakis, 2021). As parents age and children grow up, the concern for typically developing siblings becoming the caregivers for the sibling with ASD may become more of a reality (Iannuzzi et al., 2021).

Typically developing children may struggle between social acceptance and loyalty to the sibling with ASD (Schmeer et al., 2021). The relationships typically developing siblings have with peers may become impacted by the sibling's ASD diagnosis. These relationships can be impacted positively, and siblings to children with ASD may advocate for individuals with disabilities; however, it can also be negative and cause embarrassment and judgment (Iannuzzi et al., 2022). Typically developing siblings can become reluctant to share information about the sibling with ASD because of the lack of understanding peers may have for individuals with disabilities (Petalas et al., 2009). This can be especially difficult if the sibling with ASD has invisible symptoms (Moyson & Roeyers, 2011). These invisible symptoms may cause typically developing siblings to feel that they must explain and "prove" (Moyson & Roeyers, 2011, p. 51) the diagnosis of the sibling with ASD.

Siblings of children with ASD may be at a higher risk for developing mental health problems (Shtayermman & Fletcher, 2022). This may be due to the severity of ASD symptoms or challenging behavior exhibited by the child with ASD (Jones et al., 2020). Some typically developing siblings can feel symptoms of depression, anxiety, and poor adjustment. The female sibling's mental health can be more impacted than the male's, most likely because of the caregiver responsibilities. Siblings with broad autism phenotype (BAP) traits may also be at an increased risk for psychological disorders and cognitive impairments (Kurtz et al., 2023). The mental health concerns surrounding siblings of children with ASD can lead to an increased risk of suicide attempts (Shtayermman & Fletcher, 2022). Increased suicidal feelings can occur in typically developing siblings who may become the future caregiver of the sibling with ASD.

Supports can be provided to help the family and improve their quality of life (Balcells-Balcells et al., 2019). Some parents feel accurate information is not provided about ASD by formal supports (Magalhães & Pereira, 2017). Providing parents with accurate information about the ASD diagnosis and supports they can obtain may help them be better advocates for the child and have more confidence and control (Searing et al., 2015). Parents can engage in self-care or seek peer support groups (Gilson et al., 2017); they can also seek social support from grandparents (Searing et al., 2015) and spouses (Hall & Graff, 2011). Formal supports are also available to families to help provide information, assistance, and guidance (Searing et al., 2015). Families can seek the child's family doctor (Searing et al., 2015), respite care (Gilson et al., 2017), or early childhood intervention programs (Bharat et al., 2022) for professional support. Counseling (Gilson et al., 2017) and after-school care programs (Haney, 2011) can also be provided to families to help alleviate some of the stress of raising a child with an ASD diagnosis. Having a source of support can significantly improve a family's quality of life (Lei & Kantar, 2022).

Professional Application

Research shows that an ASD diagnosis may significantly impact families. Families raising a child with ASD require knowledge of supports that can be accessed to lessen the overall effect of disability on the family. Many parents with children with ASD are self-reliant and feel they are “living in a world of [their] own” (Avery et al., 2022, p. 44). Discussing the challenges associated with raising a child with ASD can be linked with perceptions of support or potential judgment and a lack of understanding from others (Searing et al., 2015). Parents may be reluctant to find support because of this fear of potential judgment. The research provided in this literature review can be used as an informational or support source for parents raising a child with a disability. This resource could be available at autism organizations, family counseling establishments, and social work practices to provide to families. Providing families with this resource may help support parents raising a child with a disability feel less isolated. Families may perceive they are alone (Avery et al., 2022) and feel a lack of understanding from others (Searing et al., 2015); however, the research provided in this paper shows that families navigating disability may be experiencing similar adversity.

Limitations of the Research

There are limitations to the research conducted in this literature review which can influence the results. First, some of the studies included in this paper had limited gender representation, as mothers of children with ASD were the majority of the individuals providing information (Avery et al., 2022; Garrido et al., 2020; Jones et al., 2017). This limitation may be due to mothers being the primary caregiver of children with ASD (Avery et al., 2022). As the responses in these studies may be primarily from the perspective of mothers, this suggests a father's perspective is limited in the literature.

Secondly, many studies did not represent racial or ethnic diversity or variability in socioeconomic status (Anderson & Butt, 2018; Avery et al., 2022; Dimachkie Nunnally et al., 2023; Rivers & Stoneman, 2003; Tomeny et al., 2016; Schmeer et a., 2021). A large number of studies primarily had participants who were mostly white with a higher socioeconomic status. This makes the results from studies less generalizable as it does not accurately represent all families with children with ASD (Avery et al., 2022). Lastly, many studies included are from 2018-2023, but there are earlier studies dating back to the early 2000s. More recent research may have significantly different findings in terms of ASD prevalence, available supports, and overall perspectives of the disorder.

Implications for Future Research

The research used in this literature review primarily focuses on the adverse impacts a child with ASD can have on family. Specific information was collected on the impact ASD has on parents (Kuhlthau et al., 2014; Roig-Vila et al., 2020; ten Hoopen et al., 2020) and on siblings (Iannuzzi et al., 2021; Jones et al., 2020; Rochefort et al., 2023; Schmeer et al., 2021). Additional information collected in this study provides information on the supports available to families who are raising a child with ASD (Gilson et al., 2017; Shepherd et al., 2020; Searing et al. 2015). Further research on this topic could include exploring if certain comorbidities associated with ASD impacted family functioning more significantly than others. Additionally, further studies could be completed on the paternal perspective of raising a child with ASD.

This literature review is primarily focused on the negative impact a child with ASD has on parents and siblings; however, further research could be completed on the positive impacts disability has on a family system.

Conclusion

This literature review provided information on the impacts ASD has on a family and the supports that can be provided to families navigating the diagnosis. From the research included in this review, it can be concluded that the disorder can impact families of children with ASD. Parents of children with ASD can be significantly affected in many areas, like health and well-being (ten Hoopen et al., 2019). Additionally, typically developing siblings can experience many difficulties associated with living with a child with ASD. They may experience negative emotions like frustration, shame, and embarrassment, which can result from the behaviors exhibited by a child with ASD (Iannuzzi et al., 2021).

It is clear that certain aspects of the diagnostic process need to be streamlined and improved. The diagnostic process can cause pain, frustration, and a sense of helplessness for families waiting for clarity on their child's symptoms (Roig-Vila et al., 2020). The timeframe between when initial symptoms are witnessed in a child to when an official diagnosis is provided to parents needs to be reduced. Parents should not have to face many obstacles when trying to receive care for a child (Zablotsky et al., 2014).

Once a child has an ASD diagnosis, more guidance and information need to be provided to parents. Parents should not have to rely on discriminating information from the Internet to understand an ASD diagnosis (Magalhães & Pereira, 2017). Post-diagnosis, parents should be provided with accurate information from health care professionals regarding the characteristics of ASD, the potential impacts the illness may have on families, and guidance on the next steps parents can take with this knowledge. Parents may require guidance to apply for funding, set up services for their children, and seek family supports. Parents should not be expected to navigate the complexity of a child's ASD disability alone.

This leads to another important conclusion from this literature review. When a child is diagnosed with ASD, professionals should encourage parents to seek support immediately. When a child is diagnosed with ASD, the overall functioning of the entire family can decline. However, implementing interventions can provide valuable support to the family. (Brockberg & Smedema, 2022). Parents need to know the importance of a support system to help manage difficult emotions resulting from parenting a child with ASD. More guidance should be provided to families proactively when the initial diagnosis occurs to prevent or better manage some of the adverse impacts that can occur while raising a child with ASD. If supports are provided to families immediately, the adverse impacts of ASD may not become as severe in some families.

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