

ABSTRACT

Title of Capstone: ON THE AUTISM SPECTRUM, PARENTS ARE BLUE:
REDUCING CAREGIVER STRESS AND
STRENGTHENING PERCEIVED SUPPORT

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Leadership, 2025

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In this study, I examined how caregiver stress and perceptions of support shape the well-being of parents raising children with autism spectrum disorder (ASD). The purpose of this work was to identify effective strategies that reduce stress, strengthen resilience, and improve family-school collaboration.

Using a systematic literature review method, I analyzed 20 peer-reviewed studies published between 2000 and 2025. The review included qualitative, quantitative, and mixed-methods research addressing caregiver stress, perceived support, stigma, and social support interventions. Three research questions guided the review: (1) What is the relationship between perceived support and self-reported stress among caregivers of children with ASD? (2) Which types of support -- emotional, informational, or instrumental -- are most associated with reduced caregiver stress? (3) What key characteristics of social support programs do caregivers identify as most beneficial in coping with stress?

Findings show that perceived support predicts caregiver well-being more strongly than the amount of support received. Respite care, culturally responsive education, peer-led groups, and stigma-reduction initiatives consistently reduced stress and improved resilience. To address these needs, I propose the Parent Support and Resilience Plan (PSRP), a four-part framework for schools that emphasizes immediate relief, caregiver education, peer leadership, and stigma reduction.

Keywords: autism spectrum disorder, caregiver stress, perceived support, stigma, stress, shame, depression

ON THE AUTISM SPECTRUM, PARENTS ARE BLUE: REDUCING CAREGIVER STRESS
AND STRENGTHENING PERCEIVED SUPPORT

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Dedication

This work is dedicated to my parents, Melvin and Kathryn Dunn, whose unwavering love, discipline, and example shaped the foundation of who I am today. You taught me the value of hard work, perseverance, and education—lessons that continue to guide me every day. Your faith in me has been a source of strength and motivation. With deepest gratitude and love, I dedicate this achievement to you both.

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List of Abbreviations

ABA – Applied Behavior Analysis

ABAS-II – Adaptive Behavior Assessment System–Second Edition

ADA – Americans with Disabilities Act

ADDM – Autism and Developmental Disabilities Monitoring Network

ADHD – Attention-Deficit/Hyperactivity Disorder

AANE – Association for Autism and Neurodiversity

ASD – Autism Spectrum Disorder

CARS – Childhood Autism Rating Scale

CBT – Cognitive Behavioral Therapy

CDC – Centers for Disease Control and Prevention

CDQ – Confidence Degree Questions

CSI – Coping Strategy Indicator

EIBI – Early Intensive Behavioral Intervention

FIQ – Family Impact Questionnaire

IEP – Individualized Education Program

MBSR – Mindfulness-Based Stress Reduction

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P2P – Peer-to-Peer

PHQ-4 – Patient Health Questionnaire–4

PSI – Parenting Stress Index

PSRP – Parent Support and Resilience Plan

PSRP-FG – Parent Support and Resilience Plan Field Guide

PSS-10 – Perceived Stress Scale–10 Item

PTSD – Post Traumatic Stress Disorder

QRS – Questionnaire on Resources and Stress

RCT – Randomized Controlled Trial

SOLACE – Stigma of Living as an Autism Carer

SMID – Severe Multiple Intellectual Disabilities

WHOQOL-BREF – World Health Organization Quality of Life–Brief

WPPSI-III – Wechsler Preschool and Primary Scale of Intelligence–Third Edition

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SECTION 1: INTRODUCTION AND IDENTIFYING THE PROBLEM

Historical and Contemporary Gaps in Caregiver Support

A substantial body of literature indicates that primary caregivers of children with autism face a persistent lack of support specifically designed for them (Papadopoulos et al., 2018). Many caregivers report experiencing shame, fear, anxiety, and chronic stress as they navigate the complexities of the autism journey, often feeling isolated and lacking adequate support (Kinnear et al., 2016). This emotional distress raises a critical and frequently overlooked question: *Who cares for the caregiver?* Throughout this paper, “autism” and “autism spectrum disorder (ASD)” are used interchangeably to reflect both clinical terminology and everyday usage. For clarity, the term “caregivers” refers to adults who hold primary responsibility for the child’s daily care, decision-making, and emotional support (e.g., parents, legal guardians).

Historically, health care policies, funding initiatives, and professional training have not adequately prioritized the health and well-being of individuals with disabilities and their families (Resch et al., 2010; Wakimizu & Fujioka, 2024). Fifty years ago, researchers conducted limited studies on disabilities and neglected the emotional and psychological needs of those impacted and their families. This gap began to shift with the emergence of family-centered approaches (Dunst & Trivette, 1986; Gallagher et al., 1983). Throughout this period, individuals with disabilities often faced considerable stigma, especially those who had mental illnesses, neurological disorders, or developmental disabilities (Corrigan & Watson, 2002; Goffman, 1963; Gray, 2002). Institutionalization was a standard solution, but others, especially those with visible physical impairments, were kept at home, out of sight. Society often pitied and feared individuals with disabilities and frequently excluded them from community life (U.S. Department of Health and Human Services, 2005).

Advances in public health and the enactment of landmark legislation such as the Americans with Disabilities Act (ADA) began to change the narrative. Today, expanding

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research and healthcare efforts focus on preventing disabilities when possible and improving access to health and wellness services for those already living with them (World Health Organization, 2022). Despite these improvements, the mental health and social support needs of caregivers remain inadequately addressed in today's system of care (U.S. Department of Health and Human Services, 2005).

The Development of Social Support Systems

This section explores how researchers and communities have developed formal and informal support systems to meet the needs of families raising children with disabilities, with ASD as the primary focus. The research includes a few non-ASD studies only when directly relevant. Those cases are marked in the text. Historically, children with disabilities and their families have faced significant stress due to societal attitudes and a lack of support (Resch et al., 2010; Skinner & Weisner, 2007). Early research often framed disability from a medical perspective, viewing it as a deficit and a source of burden for families (Meyer, 2000, as cited in Skinner & Weisner, 2007; Turnbull & Ruef, 1996, as cited in Skinner & Weisner, 2007). This problem-focused approach led researchers to focus on parents' psychological distress, especially mothers, while overlooking the wide-ranging sociocultural contexts influencing their experiences (Dykens et al., 2014; Skinner & Weisner, 2007).

In the early 1980s, Beckman (1983) conducted a foundational study linking caregiver stress to specific child behaviors rather than disability label only. Her work showed that infants who were less responsive, irritable, displayed repetitive behaviors, or required extra caregiving placed significantly higher stress on their mothers. Additionally, she found that the number of parents in the home mattered, as single mothers reported considerably more stress than those in two-parent families. These findings moved the focus away from broad assumptions about disability toward more personalized support strategies based on each family's needs.

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Expanding on this work, Beckman et al. (1986) conducted a longitudinal study of stress and support in families of preterm and full-term infants throughout the first year of their child's life. Mothers of preterm infants reported experiencing higher stress levels, but they also received more support, both formal (professional services) and informal (family and friends), which helped to relieve their burden. The researchers also noted that developmental level and the availability of support shaped caregiver stress over time. These findings provide evidence that stress is not static and that offering the correct type of support for specific challenges can reduce strain and build resiliency in families with children at risk for disability.

Subsequent studies highlighted the critical role of family support in managing the demands of raising a child with a disability (Meadan et al., 2010). Over time, interventions expanded to include medical support and social and emotional support systems, recognizing the holistic needs of these families (Neely-Barnes & Dia, 2008).

One of the most influential developments in this area of study came from Dunst and Trivette (1986) when they introduced the concept of "family-centered helping." Although outside this review's time frame, this study provides historical context and continues to inform current understandings of family-centered support. Their approach emphasized the importance of empowering families by building on their strengths and involving them in decision-making processes. These findings demonstrated that when professionals collaborate with families and acknowledge their expertise, parents report feeling more competent and supported, leading to better outcomes for both children and caregivers.

Building on their early ideas, Dunst et al. (1986) defined perceived support as a caregiver's assessment of the availability, quality, and reliability of emotional, informational, and practical assistance. They found that what matters most is how helpful and dependable the support seems to the caregiver. This idea helped influence later studies on stress by showing that support is most effective when families feel that it meets their needs.

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Further developing this foundation, Dunst et al. (1988) examined the relationship between social support and parental well-being. Their research found that parents who had access to robust social support networks experienced lower levels of stress and higher levels of satisfaction in their parenting roles. The study highlighted the significance of both formal support and informal support in enhancing parental well-being.

Complementing this work, Beckman (1991) focused on the sources and types of social support that parents of children with disabilities frequently utilize. Her research suggested that informal support systems were often more beneficial and accessible than formal services. Beckman emphasized the need for professionals to take an active role in facilitating the development of these informal networks to better support the daily caregiving demands of families. This emphasis reinforces the proactive role that professionals can play in enhancing the support available to families (Beckman, 1991; Dunst & Trivette, 1986).

In an earlier publication, Gallagher et al. (1983) provided foundational insights that still influence the field today. They were among the first to demonstrate that factors beyond the child's diagnosis or age, such as the daily demands of caregiving, financial strain, and limited support, contribute to caregiver stress. The researchers found that informal support from family, friends, and community often helps parents more than professional services. This early work introduced key ideas that researchers like Dunst and Beckman later built on, and it has continued to shape the understanding of caregiver stress and family resilience.

In another study, Dunst and Trivette (2009) explored how social support influences family functioning. They concluded that supportive relationships alleviate stress and promote positive family dynamics and resilience. Their findings suggest that social support, especially that which integrates families as active participants, such as peer-led support groups, family-centered early intervention programs, and school-based parent training workshops, is essential to the well-being of both the caregiver and children with disabilities. This research reveals how

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social support helps nurture relationships and resilience, offering families hope and encouragement.

Contemporary Perspectives on Social Support

Social support is a critical factor in the well-being of parents raising children with disabilities. It encompasses various forms of assistance, including emotional, informational, and practical support, which collectively help parents manage the unique challenges they face (Wakimizu & Fujioka, 2024, as cited in Waqar et al., 2024).

According to Neely-Barnes and Dia (2008), emotional support involves providing empathy, understanding, and encouragement. It can come from family members, friends, support groups, and mental health professionals. This type of support helps parents cope with stress, reduces feelings of isolation, and enhances their emotional resilience. Parents who participate in support groups often report feeling less alone and more understood, which can significantly improve their mental health (Neely-Barnes & Dia, 2008).

Informational support includes providing parents with knowledge and resources about their child's condition, treatment options, and available services. This type of support can come from healthcare providers, educational professionals, and advocacy organizations. Access to accurate and timely information empowers informed decision-making and effective navigation of complex systems (Austrom et al., 2014, as cited in Banbury et al., 2018; Damianakis et al., 2016, as cited in Banbury et al., 2018). Workshops and seminars on disability rights and educational strategies can equip parents with the tools they need to advocate for their child's needs.

Practical support involves tangible assistance, such as help with childcare, transportation, and daily tasks. This type of support can alleviate the physical and logistical burdens that parents often face. According to Waqar et al. (2024), family, friends, counselors, and community organizations can provide practical support, making it easier for parents to

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balance caregiving responsibilities with other aspects of their lives. Respite care, which offers temporary relief to primary caregivers, is a crucial form of practical support that can prevent caregiver burnout (Waqar et al., 2024).

Research by Feeney and Collins (2015) consistently showed that robust social support networks are associated with better outcomes for parents of children with disabilities. Parents with strong support systems reported lower levels of stress, higher levels of well-being, and greater satisfaction with their caregiving roles. Social support also contributes to positive family dynamics, as it can reduce marital tension and improve overall family functioning.

Social support through belonging and connectedness is essential for children and parents, creating feelings of personal respect and acceptance within peer groups (Riley & White, 2016). It may help parents manage the immediate challenges of caregiving and enhance their long-term resilience and well-being (Frantz et al., 2017). By creating supportive environments and providing comprehensive resources, society can play a significant role in improving the lives of these families.

Historical Perspectives on Autism and Caregiver Blame

Understanding the critical role of social support for parents of children with disabilities sets the stage for a deeper exploration into the specific experiences of parents of children with autism spectrum disorder (ASD). The journey of these parents is unique and complex, shaped by society's perceptions and medical explanations of autism. Historically, parents have navigated changing diagnostic criteria, treatment approaches, and a lack of comprehensive support systems (Feinstein, 2010; Waltz, 2015). Since the 1940s, when the condition was often misdiagnosed and poorly understood, the increase in awareness and advocacy has significantly improved how the condition is perceived. Considering the historical trend, the accounts of these parents reveal the importance of both emotional and practical support (Grinker, 2007; Ne'eman & Robertson, 2010). Silverman and Brosco (2007) emphasize that parents have endured these

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challenges while actively shaping autism research, influencing treatment models, and advancing public understanding through tireless advocacy and engagement.

Currently, about one in 36 children have been identified with autism, according to estimates from the Centers for Disease Control and Prevention's (CDC) Autism and Developmental Disabilities Monitoring (ADDM) Network (Centers for Disease Control and Prevention, 2024). While educators have made notable strides in addressing the needs of this population, efforts to support their caregivers have not kept pace. Caregivers of children with ASD often struggle to find available and accessible resources, feel stigmatized, live socially isolated, and have no network of peers in a similar situation (Lodder et al., 2019). Generally, the primary focus of support for ASD is on delivering targeted educational and community resources for the child, often at the expense of recognizing and addressing the holistic needs of the caregivers (Falk et al., 2014). According to Silva and Schalock (2012) as cited in Chiang (2014), parents of children with ASD experience significantly higher levels of stress compared to parents of children with typical development and those with other developmental delays. Together, the high levels of stress for parents of children with ASD and the evidence on the critical role of family support suggest an urgent need to prioritize comprehensive, caregiver-centered practices for this population (Hayes & Watson, 2013; Meadan et al., 2010).

Despite growing attention to autism services for children, the mental health and support needs of caregivers remain insufficiently addressed. Research shows that high levels of parenting stress are consistently linked to limited access to effective supports, highlighting the importance of perceived support in alleviating these challenges (Hayes & Watson, 2013; Wakimizu & Fujioka, 2024). This review examines how perceived support influences caregiver stress, with a focus on identifying effective support models.

To understand why caregivers are still often overlooked, it is essential to examine the history of stigma surrounding autism. In the past, theories and cultural beliefs, especially those

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that blamed parents for their child's diagnosis, shaped societal views of autism and left lasting effects on families (Rivard et al., 2014). These parental-blame frameworks, stereotypes, discrimination, and systemic inequalities continue to affect how caregivers feel and are treated today (Corrigan & Watson, 2002; Goffman, 1963; Gray 2002).

These historical misconceptions date back to the 1940s, when the “refrigerator mother” theory emerged as an attempt to explain the cause of autism. Leo Kanner, one of the first U.S. child psychiatrists to define autism as a distinct condition, speculated that emotionally distant and unresponsive parenting contributed to its development (Waltz, 2015). Psychologist Bruno Bettelheim further popularized this idea by arguing that a lack of maternal warmth led to the development of autistic behaviors in children. His 1967 book, *The Empty Fortress: Infantile Autism and the Birth of the Self*, significantly advanced the refrigerator mother theory and reinforced maternal blame. As Shapin (2016) noted, many professionals often advised parents to place their children in institutions and forget about them. Scholars accepted the theory, and Bettelheim's views had a lasting cultural impact and contributed to deeply established beliefs about mother-blame.

Today, the scientific community overwhelmingly recognizes autism as a neurodevelopmental condition with strong genetic roots. Goldstein (2025) explains that current research attributes autism to a combination of genetic and environmental factors, not parenting style. Waltz (2015) emphasizes that the early theorists formed their ideas more in response to social and institutional biases than based on empirical evidence. By the late 1970s, as research increasingly pointed to genetic and environmental factors, not parenting style, the refrigerator mother theory was widely discredited. Despite being scientifically rejected, some of these outdated beliefs remained in society. As a result, many caregivers, especially mothers, continued to face stigma, self-doubt, and blame related to their child's diagnosis (Gray, 2002).

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The effects of past experiences highlight why outdated beliefs, even when refuted, continue to shape caregiver perceptions and emotional responses. Historical accounts show that parental-blame theories and deficit views of autism have left a long-lasting influence on how families are perceived and how they internalize stigma (Corrigan & Watson, 2002; Gray, 2002; Rivard et al., 2014). It also stresses the need to better understand how these experiences occur in real-world educational and family settings, where gaps in support continue to affect caregivers directly (Meadan et al., 2010; Resch et al., 2010). Collectively, these lasting effects emphasize the urgency to investigate how today's support systems, or their absence, impact caregiver well-being (Hayes & Watson, 2013; Wakimizu & Fujioka, 2024).

Rationale for the Problem of Practice

This problem of practice emerged from my 27 years of experience as a special educator, during which I have consistently witnessed the emotional toll that an autism diagnosis can have on caregivers. Many parents and guardians have shared feelings of isolation, uncertainty, and discouragement. These experiences reflect widespread trends in literature, which show that parents often receive limited emotional guidance following diagnosis, contributing to extended stress and self-blame (Meadan et al., 2010; Resch et al., 2010). A recurring theme in these interactions has been self-blame, with caregivers often asking questions such as, "Why did this happen?" or "Did I do something wrong during my pregnancy?" Pleas for guidance usually follow these deeply personal expressions of distress and despair: "What do I do now?"

Over time, these experiences have shaped how I see my role as an educator and advocate. I realize that many families often do not receive the emotional help they need after their child is diagnosed with autism. Even though caregivers play a key role in their child's development, professionals and systems sometimes overlook the caregivers' own mental health and well-being. Recognizing the continuous gaps in caregiver support led me to focus on how we can realistically improve support systems to meet the actual needs of caregivers. My goal is

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to explore ways to reduce caregiver stress and help families feel more supported and prepared for their journey. These personal and professional observations laid the foundation for this study, which intends to critically examine the types of support that are most effective in meeting the needs of caregivers.

Theoretical Foundation

To better understand the patterns observed across these studies, this capstone uses four key theories: Family Systems Theory, Stress and Coping Theory, Ecological Systems Theory, and the ABCX Model. Each one helps explain how stress and support influence caregiver well-being.

Family Systems Theory (Bowen, 1978; Minuchin, 1974) views the family as a single, connected unit made up of smaller parts or subsystems. The unit includes the relationship between parents, the bond between parent and child, and the connections among siblings. Stress for one member of the family inevitably affects everyone else. For example, when a child is diagnosed with autism, it affects the entire family structure. It flows into other relationships. Parents may feel a strain in their marriage, their parenting roles may change, and siblings may feel neglected or worried.

The model explains these dynamics in terms of inputs, processes, and outputs. Inputs include the family's structure, characteristics of its members, and any special challenges, such as raising a child with a disability. Processes involve the daily interactions among family members, the way subsystems function (marital, parental, sibling), and the family's exchanges with society. Outputs are the family's functions, such as providing affection, daily care, socialization, and economic stability, shaped by both inputs and the processes. The family also changes over the lifespan. For example, over time, the family structure may change with the addition of other children or as the consequence of divorce or remarriage.

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Two other important ideas in the Family Systems Theory are cohesion (the level of emotional closeness or independence among family members) and adaptability (the family's ability to change roles, rules, and structures in response to stress). Families vary with respect to both these dimensions. Families that find a balance between closeness and independence, and that adapt without becoming rigid or chaotic are better able to cope with challenges. These qualities are especially important throughout the family life cycle, as needs change over time.

A key idea in this theory is the role of boundaries, like invisible lines that define how family members relate to one another and to people outside the family. Healthy boundaries provide families balance through flexibility, support, and the provision of resources. Parents can support their child while still taking care of their relationship and siblings can stay connected without feeling overwhelmed. If boundaries are too strict, family members may feel distant from each other. If they are too loose, stress can spread easier, leaving everyone exhausted.

This perspective shows why parental stress impacts the entire family system. Family connections, roles, and boundaries shape how stress is experienced and determine whether it creates conflict or helps the family unite. Kinnear et al. (2016) support this view, showing that stigma linked to autism often extends beyond the child, to parents and siblings. It creates isolation and exclusion in the family system and increases the difficulty of family life.

Lazarus & Folkman's (1984) *Stress and Coping Theory* explains stress as the result of how people view a situation and the resources they believe they have to handle it. Stress happens not just because something is difficult, but because a person feels that what is being asked of them is more than they can manage. First, people evaluate a situation to decide whether it is harmless, positive, or stressful. Next, they think about what options and support they have available. If they feel unprepared or under-resourced, stress increases. To respond, people use two main types of coping: 1) problem-focused coping, where they try to solve or

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change the situation, and 2) emotion-focused coping, where they work on managing their feelings about it.

For parents of children with disabilities, this theory shows why the belief support is available is critical. Caregivers benefit most when they feel that help is reliable, practical, and truly meets their needs. Research has found that this sense of perceived support predicts caregiver well-being more strongly than the actual amount of support received (Meadan et al., 2010; Resch et al., 2010).

Ecological Systems Theory was first developed by Bronfenbrenner (1979) to explain child development, but it can also help explain caregiver stress. Although it was originally developed for issues related to children's growth and development, it has also been applied to families (Beckman et al., 1998; Dunst et al., 2000; Turnbull et al., 1994). When applied to families, this theory posits that families are influenced by many layers of their environment, each of which can influence the others. The microsystem comprises those settings in which the child is directly involved, such as the family, the classroom, and the neighborhood. The mesosystem is how those settings connect, for example the relationship between parents and teachers or between home and healthcare providers. The exosystem involves larger systems the child may not directly take part in but still affect the family, such as workplace demands, school district policies, or healthcare systems. The macrosystem includes the broader cultural and political environment, including societal attitudes about autism and disability that can either add stigma or create acceptance.

Bronfenbrenner (1985) later expanded this theory which he called the Bioecological Model to include the chronosystem, which looks at how these layers change over time (e.g., children grow, services change, policies are updated, etc.) He also introduced the idea of proximal processes, the everyday interactions like parent-child communication, sibling support, or teacher feedback that drive development and shape family well-being. While this theory

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began as a way to understand children's growth, it also shows why caregiver stress cannot be understood in isolation. Families are part of overlapping systems, and changes in one system impact the others. These changes either add to stress or help families cope. In the context of this paper, negative cultural attitudes about autism in the macrosystem can increase stigma, but community-wide acceptance initiatives can promote caregiver pride and reduce isolation.

The *ABCX Model* (Hill, 1949), later expanded into the *Double ABCX Model* by McCubbin & Patterson (1983), adds a valuable framework for understanding how families handle stress and adapt over time. In this model, A represents the stressor event (e.g., a child's diagnosis, a military deployment, the birth of another child, the death of a family member), B represents the family's available resources (e.g., emotional support, finances, or professional services), C is the family's perception of the event (e.g., whether they view the diagnosis as manageable or overwhelming), and X is the outcome, either a crisis or successful adaptation. McCubbin and Patterson extended this model further with the Double ABCX Model, suggesting that family adjustment is not a one-time event, but an ongoing process that changes over time. As families face new challenges or find new sources of support, any part of the model, A (the stressor), B (the resources), C (the perception), or X (the outcome) can shift. For example, finding a helpful support group or getting access to respite care can change how families view their situation and give them more tools to cope. The model helps explain why some families adapt and become resilient while others face recurring crises. By recognizing that family life keeps changing, the Double ABCX Model shows why it is essential to provide families with both practical and emotional support that is enduring and adaptable to their needs. This perspective is consistent with findings from Damianakis et al. (2016), who found that caregivers of young adults with traumatic brain injury adapted over time by seeking new resources, reframing their experiences, and building resilience through support group participation.

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Table 1 summarizes these four theories. It outlines their core focus and shows how each one helps explain caregiver stress and perceived support.

Table 1

Theory Comparison Table

Theory	Core Focus	Relevance to Caregiver Stress
Family Systems Theory (Bowen, 1978; Minuchin, 1974)	Families are made up of interconnected subsystems (parent-parent, parent-child, sibling relationships) with boundaries that shape how members relate.	Stress in one member (such as a child's diagnosis) spreads through the whole family, affecting marriage, parenting roles, and sibling well-being depending on how healthy or rigid boundaries are.
Stress and Coping Theory (Lazarus & Folkman, 1984)	Stress occurs when demands feel greater than available resources; coping depends on how individuals perceive support.	Caregivers' belief that support is reliable and accessible is often more important than the actual amount of help received.
Ecological Systems Theory (Bronfenbrenner, 1979)	Development and stress are shaped by interacting layers: microsystem (family, classroom), mesosystem (family-professionals), exosystem (indirect systems like policies or workplaces), macrosystem (cultural and political environment), chronosystem (changes over time), and proximal processes (everyday interactions).	Caregiver stress is influenced by both immediate settings and larger systems, with changes in one layer impacts others to either add stress or promote resilience.
ABCX/Double ABCX Model (Hill, 1949; McCubbin & Patterson, 1983)	Family adaptation depends on the stress (A), available resources (B), perception of the event (C), and outcomes (X). The Double ABCX shows that this process takes place over time.	Families adapt differently depending on resources, outlook, and supports; outcomes range from crisis to resilience, with new supports (like respite care or peer groups) changing how families cope.

Note: Table 1 provides a summary of the four theoretical frameworks. It highlights the main focus of each theory and explains its relevance to understanding caregiver stress and perceived support.

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Together, these four theories help explain the relationship between caregiver stress and perceived support. They guide the research questions that follow and frame the discussion of which support systems are most effective in helping families reduce stress and strengthen caregiver resilience.

Statement of Purpose and Guiding Research Questions

Caring for a child with autism or other disabilities presents significant emotional, psychological, and logistical challenges for parents and caregivers (Hayes & Watson, 2013; Resch et al., 2010). A complex connection between stressors and support systems forms these experiences (Meadan et al., 2010; Rivard et al., 2014). A deeper understanding of the factors that influence caregiver well-being is essential for designing effective, practical support services (Lodder et al., 2020; Wakimizu & Fujioka, 2024). Therefore, the purpose of this study is to investigate how perceived support influences caregiver stress among parents of children with ASD and other disabilities. It aims to examine the most effective forms of support and the core features of successful programs that strengthen caregiver well-being. The primary focus of this study is ASD. Non-ASD studies are cited only when the same factors related to stress and support apply (e.g., perceived support, peer connection, videoconferencing delivery). Those instances are identified in the text.

This study seeks to address the following guiding research questions (RQ):

1. What is the relationship between perceived support and self-reported stress among caregivers of children with ASD?
2. Which types of support -- emotional, informational, or instrumental -- are most associated with reduced caregiver stress?
3. What key characteristics of social support programs do caregivers identify as most beneficial in coping with stress?

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In addition, identifying which types of support are most strongly associated with reduced caregiver stress will inform the development of targeted, practical interventions that specifically address the caregivers' perceived needs. Analyzing the key features of effective support programs will provide insights into what makes these services meaningful and sustainable from the caregiver's perspective. Together, these findings will serve as a guide for the creation of accessible, empirically supported systems that strengthen caregiver well-being by promoting mental health, emotional resilience, and improving their overall quality of life.

To answer these questions, this capstone used a systematic review. This approach allowed me to gather and compare research on the experiences of caregivers raising children with ASD. It includes closely related disability studies only when the same stress and support factors apply; those cases are identified in the text. The goal was to advance a comprehensive understanding of these issues and offer evidence-based recommendations for improving the quality and accessibility of support services. The following section outlines the methods used to identify, screen, and analyze relevant studies that inform the findings and recommendations of this review.

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SECTION 2: COMPREHENSIVE RESEARCH REVIEW

Search Strategy

To ensure a comprehensive and systematic literature review, I used multiple databases and search engines. The primary academic databases included ERIC, APA PsycINFO, EBSCOhost, and PubMed. I then conducted additional searches through Google Scholar to access relevant gray literature and hand-searched citations. The What Works Clearinghouse provided evidence-based practices and interventions aligned with the research questions.

In addition to academic databases, I examined materials for professionals who work with families to capture real-life experiences and practical support strategies. These included websites and publications such as *Autism Speaks* and *Psychology Today*, selected for their focus on autism-specific mental health and caregiver well-being. I also examined organizational materials from the Association for Autism and Neurodiversity (AANE) for their reports and toolkits on caregiver experiences and best practices.

I implemented search protocol using Boolean operators and search terms including: “autism,” “ASD,” “disabilities,” “parents,” “caregivers,” “stigma,” “stress,” “anxiety,” “depression,” “shame,” “guilt,” “mental health,” “trauma,” “PTSD,” “perceived support,” and “actual support.” The literature search extended across PsycINFO, PubMed, EBSCO, Web of Science, and Google Scholar.

Hand Searches

In addition to the electronic database searches, the review included hand searching to identify additional relevant studies not identified through keyword-based search results. This process resulted in the inclusion of nine articles. The search located four articles: Christi et al. (2022), Dunst and Trivette (1986), Gallagher et al. (1983) and Lee et al. (2023), through a combination of searching reference lists, reviewing journal issues, and using Google Scholar. A

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backward citation search from the Lee article identified one additional study, Meadan et al. (2010).

I excluded papers that were only theoretical without applied or tested ideas. However, several foundational articles identified through hand searching were referenced to provide historical and conceptual grounding. For example, Dunst and Trivette (1986) and Gallagher et al. (1983) were published before 2000, they provided valuable background for understanding key ideas relevant to this research. These authors used empirical theory to help explain the relationship between support, caregiver stress, and parenting behavior. However, their work was not critiqued as part of the comprehensive research review.

I incorporated three more studies, Resch et al. (2010), Rivard et al. (2014), and Russa et al. (2014); after a focused review, I identified their close connection to key topics such as caregiver stress, social support, and family-centered care. These articles contribute historical and theoretical context to caregiver experiences. Although the articles do not cite one another, they present a wider picture of the literature on recommended support systems for families of children with autism and other disabilities.

Backward Citation Tracking

I also used backward citation tracking, beginning with Lodder et al. (2020) as the foundational article. References from Lodder et al. led to multiple studies relevant to the research questions. This process identified and included Banbury et al. (2018), Corrigan and Watson (2002), Damianakis et al. (2016), Frantz et al. (2017), Gray (2002), Hayes and Watson (2013), Kinnear et al. (2016), Papadopoulos et al. (2018), and Yanos et al. (2008). These studies added valuable information to the discussion on caregiver stigma, mental health, stress, and practical support programs. Lodder's reference list revealed suitable, high-quality studies that did not appear in the original database searches. Backward citation tracking produced nine peer-reviewed articles. I selected and integrated these sources based on their relevance to

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caregiver stigma, perceived support, mental health outcomes, and effective psychosocial interventions.

Screening and Study Selection

The electronic database search strategies produced a total of 218 articles—215 from the primary search and three from a secondary search on caregiver self-perception and support outcomes. I removed duplicates and applied a two-stage screening process. The first stage reviewed titles and abstracts for relevance, narrowing the pool to 24 full-text articles. The second stage involved a more detailed review that excluded studies using single-subject designs, included fewer than 90% caregivers of school-aged children with ASD, and those lacking methodological rigor or relevance to the research questions. Six studies from the database search met the final criteria for thematic synthesis.

Manual methods added 18 studies to the review. Of these, nine were identified through hand searches of reference lists and key journals, while another nine emerged from backward citation tracking beginning with Lodder et al. (2020). These additional sources enriched the review by incorporating both foundational and recent studies related to caregiver stress, support systems, and stigma. In total, 24 studies were selected for detailed review. However, only 20 were selected for final inclusion in the comprehensive research review.

Data Analysis and Synthesis

I screened studies in two stages: title/abstract review and full-text review. After finalizing the selection, I examined each article to identify common topics and patterns related to caregiver stress, perceived support, and characteristics of effective support programs. A thematic synthesis organized the findings by shared ideas or themes, providing easier comparisons across studies and supporting meaningful conclusions. Relevant articles from both databases and manual searches underwent evaluation according to specific inclusion and exclusion criteria.

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Inclusion and Exclusion Criteria

The review included empirical, peer-reviewed studies published in English between 2000 and 2025 that focused on parents or caregivers of children diagnosed with autism or other developmental disabilities and examined psychological or emotional challenges such as stress, anxiety, depression, stigma, or caregiver support. Studies involving non-ASD caregiving populations were included only when the same factors applied (e.g., perceived support, peer connection, digital group delivery). Those cases are identified in the text.

Although I prioritized peer-reviewed empirical studies, I included Russa et al. (2014) due to its direct relevance and practical insight into systems-level barriers faced by families seeking ASD support. While not an empirical study, the article offered a well-supported combination of policy recommendations, identified service gaps, and discussed implementation challenges that align with the review's themes.

This study included historical or foundational articles published before 2000 if they provided essential context to the research. The review excluded purely theoretical papers, opinion pieces, or studies not focused on caregivers of children with disabilities. Exceptions were made for reputable organizational publications, such as those from AANE, when they contributed practical caregiver insight. As explained in the inclusion and exclusion criteria, purely theoretical works were excluded from this review. Exceptions were made for foundational studies that applied theory in research-based ways.

This review covered a 25-year span (2000-2025) to provide a full picture of how research on caregiver stress, support, and stigma has developed over time. Earlier studies helped define key ideas and tools still used today, while more recent work reflects new practices such as digital supports and culturally responsive programs. Although this is a wide range, strict criteria kept the focus on studies with strong methods and direct relevance. A few pre-2000

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works were included as background for historical context, not as part of the main body of studies.

Limitations

The decision to use a 25-year span (2000-2025) for this review adds range but also brings certain limitations. While the span added strength by covering both early and recent work, it also meant some studies were based on older diagnostic criteria or service systems. This risk was reduced by applying strict criteria and by using pre-2000 works only for context, not as part of the main set of studies. Despite the use of multiple search strategies, the review faced several limitations. First, limiting the search to English-language studies may have excluded valuable research from other cultural contexts. Second, while reputable organizational sources reflected real-life caregiver experiences, these sources may not meet the same research standards as peer-reviewed journal articles. Finally, keyword search limitations may have omitted relevant studies. Researchers should consider these factors when applying the findings to other caregiver populations or contexts.

Review of the Literature

Following the methodology, this literature review begins with research on stigma to explain the emotional and social challenges that shape caregiver stress and then reviews studies addressing each guiding research question introduced in Section One.

The Role of Stigma in Caregiver Stress

Before examining the research that focuses directly on caregiver stress, it is crucial to understand how stigma contributes to that stress. A foundational study by Gray (2002) studied how mothers of children with autism often felt judged, blamed, and excluded by others. These experiences contributed to many parents feeling isolated and unsure of themselves. Building on this idea, Papadopoulos et al. (2018) reviewed multiple studies and created a model to explain how stigma affects caregivers. They described three types of stigmas that can deplete a

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caregiver's confidence and emotional health: public, courtesy, and affiliate. Together, these studies show that stigma is more than a social issue, as it can seriously affect mental well-being. Their findings help explain why support systems must address stigma in order to reduce caregiver stress.

Gray's (2002) work provides an early and insightful exploration into how stigma influences caregiver identity and well-being. He conducted an ethnographic study examining stigma among parents of children with high-functioning autism, with specific attention to the judgment often directed toward mothers, an influence later referred to in the literature as "mother-blame" (pp. 744-745). Gray purposefully selected Australian participants, 32 mothers and 21 fathers, based on their caregiving experience and prior exposure to stigma. Researchers interviewed both parents in 21 families. The study took place in homes and community settings to examine the social experience of these families. He conducted in-depth, semi-structured interviews, typically lasting between two and three hours, but some ranged from one to over four hours. These conversations provided parents with an opportunity to describe their lived experiences and how stigma shaped their private lives and public interactions. Gray established trustworthiness through prolonged engagement, peer debriefing, and detailed descriptions.

Although Gray (2002) focused on families of children with high-functioning autism, this research is still highly relevant to understanding caregiver stress. Because autism does not inherently signal low cognitive ability, these families often navigate mainstream environments where their child's disability is less visible. This invisibility increases exposure to judgment and mother-blame. His findings reinforce that stigma affects caregivers across the spectrum, not only those raising children with higher support needs.

The issues discussed in the interviews covered several key areas, including the onset of symptoms, the referral experience and diagnosis, the nature of the child's present symptoms, and the widespread effects of autism on the family. The data were transcribed and thematically

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analyzed. Data analysis included coding, memoing, and classification of codes. Gray (2002) triangulated across interviews and observations to label emerging themes. This process resulted in two major themes related to stigma: enacted stigma and felt stigma. These stigmas often led parents to withdraw socially, question their self-worth, and blame themselves for their child's differences. Mothers carried most of the social scrutiny, a pattern the author linked to outdated cultural narratives that wrongfully criticize female caregivers.

Gray (2002) concluded that stigma, especially when grounded in outdated assumptions, can have long-lasting psychological consequences on caregivers, including chronic feelings of embarrassment, isolation, and parental inadequacy. Participants in the study reported cycles of social withdrawal, emotional distress after public incidents, and persistent anxiety about being judged for their child's behavior. His findings called for improved education, greater public understanding, and caregiver support systems that actively challenge stigmatizing discussions.

Goffman's (1963) Stigma Theory provided the conceptual foundation for Gray's (2002) analysis. Where Gray documented how caregivers experience stigma in daily life, Goffman's work offered the theoretical structure to explain these patterns. He conceptualized stigma as a social process in which certain attributes can lead others to view an individual as inferior. Goffman further distinguished between *enacted stigma*, which comes from how others treat a person, and *felt stigma*, the shame or fear a person feels inside. This distinction offers deeper insight into the psychological toll of stigma.

Guided by this framework, Gray (2002) drew on this framework to interpret his own findings, demonstrating how caregivers face both public judgment and internal shame. By applying Goffman's distinctions, Gray clarified how stigma shapes caregivers' emotional responses and sense of identity. His study was one of the first qualitative investigations to examine how caregivers of children with disabilities navigate both forms of stigma in their daily

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lives. The use of personal stories made the findings more powerful by showing how stigma affects everyday caregiving.

However, the study had notable limitations, including the lack of demographic diversity, consisting primarily of Australian families from the Brisbane metropolitan area, with limited representation of varied cultural, ethnic, or socioeconomic backgrounds. These factors may restrict the applicability of the findings. Additionally, Gray (2002) provided minimal details regarding coding procedures or the use of member checking, which may affect the credibility and trustworthiness of the data analysis process. Even though the study had some limitations, the long and detailed interviews lasting one to four hours showed that participants were highly engaged, which helped the researcher gather meaningful and in-depth information. Despite these limitations, the findings have strong real-world relevance and contribute meaningfully to its social validity.

Additionally, Gray's (2002) study spanned 10 years, providing a longitudinal perspective into how stigma affects caregiver well-being over time. More than half of the 53 parents interviewed reported significant anxiety or depression, and nearly one-third were receiving psychotherapy or medication to cope. High caregiving demands and repeated exposure to public misunderstanding and blame contributed to these outcomes. The severity of the child's symptoms also played a role. Parents of children who were more aggressive or disruptive described greater enacted stigma, such as being stared at or excluded from social events. Mothers were more likely than fathers to experience both felt and enacted stigma.

Although Gray (2002) analytically distinguished between felt and enacted stigma, many parents described them in overlapping ways, combining internal feelings of shame with perceived judgment from others. Over time, some parents described becoming more resilient. As they built support systems and gained confidence, the emotional impact of stigma became less overwhelming, even when the behaviors of others remained the same. Gray's insights

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remain relevant today, laying the groundwork for more recent research that directly links stigma to measurable declines in caregiver mental health. To fully understand the caregiver experience, it is essential to examine the historical and ongoing role of blame and stigma in shaping mental health outcomes.

Expanding on the stigma-focused foundation established by Gray (2002), Papadopoulos et al. (2018) conducted a systematic review exploring the connection between ASD stigma and informal caregiver mental health. They drew from 12 empirical studies published between 1990 and 2017, comprising a total sample of 1,442 caregivers. Papadopoulos and colleagues combined qualitative and quantitative findings to better understand how stigma influenced caregiver well-being. The primary goal of the review was to develop a new theoretical framework to explain this complex and underexplored connection.

Papadopoulos et al. (2018) identified three primary forms of stigma that contribute to caregiver distress: *public*, *courtesy*, and *affiliate* stigma. Public stigma involves societal attitudes that stereotype and exclude individuals associated with autism, often leading caregivers to feel ashamed and isolated. Courtesy stigma refers to the indirect social punishment caregivers face, including strained relationships and reduced community support due to their association with someone who is stigmatized. Affiliate stigma occurs when caregivers internalize negative messages, leading to feelings of guilt, low self-esteem, and feelings of worthlessness. The authors emphasized how these forms of stigma interact and shape the psychological well-being of caregivers.

Papadopoulos and colleagues (2018) used a rigorous search process and multiple reviewers for independent data extraction to reduce bias and confirm their findings. They used the Joanna Briggs Institute (JBI) quality appraisal tool to ensure methodological quality of each included study. The JBI tool is a standardized checklist designed to evaluate methodological rigor and minimize bias across different study designs (Joanna Briggs Institute, 2017). Inter-

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rater reliability ($k = .745$) showed strong agreement among reviewers, adding credibility to the synthesis. The inclusion of both qualitative and quantitative studies allowed for a deeper understanding of how stigma affects caregivers. The researchers used a structured process to code data, identify patterns, and summarize key themes. Emergent themes included social withdrawal due to public judgment, strained family relationships resulting from courtesy stigma, and self-blame connected to internalized or affiliate stigma. These different forms of stigma often overlapped. For instance, public stigma frequently led to social exclusion, which increased isolation and internal shame. Together, these experiences increased caregiver stress, causing continuous emotional strain.

One significant contribution of Papadopoulos et al.'s (2018) study was the introduction of a new theoretical model called the "Caregiver Stigma Pathway Model." This framework showed how different forms of stigma lead to internal beliefs of shame and low self-worth, reducing caregiver resilience, lowering self-esteem, and increasing emotional vulnerability. Over time, caregivers become more likely to avoid social interaction and support services. The model revealed the need for specific interventions that address the emotional damage caused by stigma.

The study also had limitations. Studies published only in English or Dutch narrowed the generalizability of the findings to specific cultural contexts. Additionally, Papadopoulos et al. (2018) did not clearly explain their own perspective, which may have influenced how the results were presented and understood. Despite these limitations, the review's clear methods and introduction of a new theoretical model make it an essential contribution to the discussion of autism caregiving and mental health.

Papadopoulos and colleagues (2018) concluded that support programs for caregivers must directly address stigma. To reduce stigma, providers must do more than offer education or respite services; they must deliver these resources within a supportive framework. The authors

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called for the development of culturally responsive, trauma-informed interventions that promote social inclusion, challenge harmful narratives, and rebuild caregivers' sense of identity and competence.

Gray (2002) and Papadopoulos et al. (2018) present a clear and progressive understanding of how stigma affects the emotional well-being of caregivers. Gray focused on the personal, day-to-day experiences of judgment, especially for mothers, showing how social stigma can lead to isolation and self-doubt. In contrast, Papadopoulos et al. took a broader view by analyzing findings from multiple studies and creating a model that explains how public and social judgment can lead caregivers to feel ashamed or inadequate. While Gray captured the immediate emotional difficulty of stigma in everyday life, Papadopoulos et al. explained how these feelings accumulate within the chronosystem (Bronfenbrenner, 1985), building up over time to weaken caregiver mental health. Both studies show that stigma is more than a personal issue, it is a systemic concern that requires targeted intervention. Adding to their work, the following section explores the everyday emotional, relational, and systemic challenges encountered by parents of children with ASD.

Stigma plays a significant role in shaping caregiver well-being, but it is only part of the problem. Many caregivers also face persistent stress from the everyday demands of raising a child with ASD, especially when support is difficult to attain. The following section moves from stigma to stress, beginning with a focus on the elevated stress experienced by caregivers of children with ASD compared to other parents. This discussion and the subsequent studies help to clarify the sources of this stress and how support systems can help reduce its impact.

RQ 1: What is the relationship between perceived support and self-reported stress among caregivers of children with ASD?

Building on the previous discussion of how stigma historically shaped the emotional experiences of caregivers, it is also necessary to examine how stress affects parents and

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caregivers of children with ASD today. As established, caregivers often feel emotionally impacted due to a lack of understanding, limited access to services, and feelings of isolation (Gray, 2002; Resch et al., 2010). These experiences show that many of the stigmas faced by caregivers in the past still affect families today, adding to ongoing mental health challenges (Rivard et al., 2014). To better support caregivers, it is essential to understand the extent and origins of their stress. Current research identifies several predictors of that stress, including the severity of a child's needs, socioeconomic status, or gaps in formal support (Hayes & Watson, 2013; Meadan et al., 2010). The following studies examine these dynamics, beginning with how stress levels among caregivers of students with ASD compare to other parent populations, and then exploring systemic and environmental factors that contribute to caregiver burden. This historical and theoretical foundation informs current research on stress predictors and the role of perceived support.

Hayes and Watson (2013) conducted a meta-analysis examining the stress levels of parents raising children with ASD compared to parents of typically developing children and those with other disabilities. The researchers analyzed 15 quantitative studies published between 1985 and 2008, using a random-effects model to assess the overall effect size of parenting stress. The studies all used well-established, validated tools such as the Parenting Stress Index (PSI), Family Impact Questionnaire (FIQ), and the Questionnaire on Resources and Stress (QRS). The PSI (Abidin, 1983) is a self-report questionnaire that evaluates sources of stress in the parent-child system through subscales addressing child behavior, parental distress, and dysfunctional interactions. The FIQ (Donenberg & Baker, 1993) focuses on the perceived negative emotional and relational impact of parenting a child with special needs. The QRS (Holroyd, 1974, 1987) assesses family challenges such as pessimism, social support, physical incapacitation, and emotional strain. These instruments offered broad and detailed

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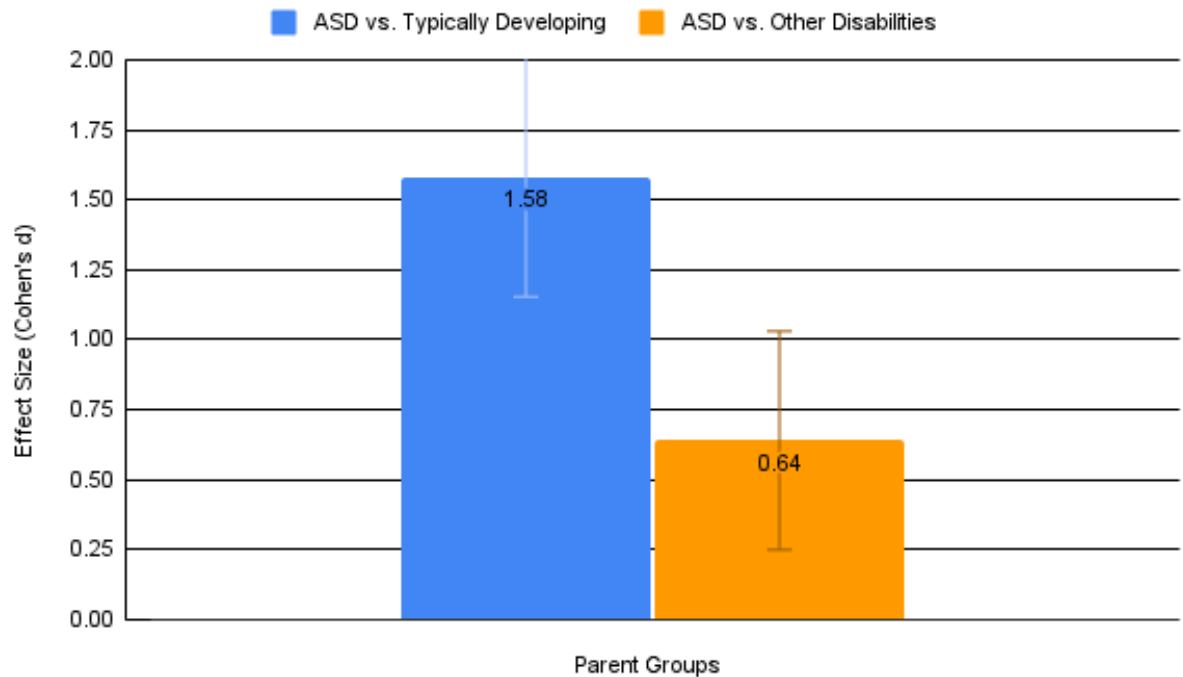
insight into caregiver stress, allowing the researchers to develop comparisons across diverse family systems.

Their data analysis showed that parents of children with ASD consistently reported higher levels of parenting stress. The unique behavioral challenges associated with ASD, such as rigidity, communication difficulties, and unpredictable behaviors, paired with systemic barriers like delays in diagnosis and a lack of individualized services, were linked to the elevated stress. When compared to parents of typically developing children, parents of children with ASD reported significantly more stress, with a large effect size of 1.58 (95% CI = 1.16 to 2.00, $p < .001$). Comparing parents of children with ASD to parents of children with other disabilities, a similar but more negligible effect was observed with an effect size of 0.64 (95% CI = 0.25 to 1.03, $p < .001$), again showing greater stress among the ASD group. These results are visually summarized in Figure 1: Comparative Effect Sizes in Parenting Stress Across Groups. Hayes and Watson (2013) emphasized that these higher stress levels were associated with poorer outcomes for both caregivers and children, including increased mental health challenges, parenting fatigue, and family conflict. They reached this conclusion by examining results from multiple studies in their review. These studies showed clear connections between elevated parenting stress and negative outcomes like deteriorating mental health, increased parenting fatigue, and greater family conflict.

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Figure 1

Comparative Effect Sizes in Parenting Stress Across Groups



Note: This figure illustrates the extent of parenting stress reported by parents of children with ASD, as compared to parents of typically developing children and those with other disabilities. Larger effect sizes indicate greater reported stress. These data are based on Hayes and Watson's (2013) meta-analysis.

The strength of the study is its comprehensive and methodologically rigorous design. Hayes and Watson (2013) applied strict inclusion criteria and used well-validated stress tools and random-effects models to account for variation across studies. Additionally, they considered the contextual factors that uniquely burden ASD caregivers, such as social stigma and limited support systems. There were also limitations. Most of the studies relied heavily on maternal reports, which may not fully capture stress experiences across caregivers. Additionally, there was limited diversity in the sample population, as the studies were predominantly from Western

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cultures, limiting the generalizability of findings to families from other cultural or socioeconomic backgrounds. Lastly, publication bias may have influenced the results, as studies reporting higher stress levels may have been more likely to be published and included in the analysis.

Hayes and Watson (2013) provided empirical evidence that caregivers of children with ASD experience elevated levels of parenting stress compared to other groups. Their findings highlight the need for emotional and psychological support systems tailored to the particular challenges these caregivers face. Although the meta-analysis established heightened stress levels, it did not examine the specific child, family, or systemic variables that contributed to these outcomes. The following studies address this gap by exploring predictors of caregiver stress, particularly the role of support.

Evidence from multiple studies shows that caregivers who receive consistent support through counseling, parent education, or peer connection report lower stress and increased confidence (Damianakis et al., 2016; Meadan et al., 2010; Resch et al., 2010). These findings support the idea that both emotional and practical support affect how well families manage the challenges of raising a child with a disability. Specifically, Dunst et al. (1986) provided an influential definition of perceived support, describing it as a caregiver's assessment of the availability, quality, and reliability of emotional, informational, and practical assistance. Their early work continues to influence current research and shows that strong support systems can reduce caregiver stress and promote resilience.

Adding a systems-wide perspective to the discussion, Meadan et al. (2010) provide a family-level view of how stress and support interact within households raising children with ASD. They conducted a comprehensive literature review exploring how stress affects the marital relationship, parent-child interactions, and sibling dynamics. The authors used ERIC and PsycINFO databases, using keywords such as "autism," "stress," "coping," "support," "mother," "father," "siblings," and "adjustment." Articles were selected if they were peer-reviewed,

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published in English between 2000 and 2007, empirical, and focused on parents or siblings of children with ASD. Meadan et al. conducted ancestral searches to identify additional relevant studies through reference lists.

Meadan et al.'s (2010) search yielded 57 peer-reviewed journal articles, screened to exclude studies that involved small ASD sample sizes or that focused only on individuals with ASD. The final selection concentrated on studies that aligned with the first three subsystems in their framework—marital, parental, and sibling subsystems—as well as coping strategies and sources of support. Rather than applying qualitative or quantitative synthesis methods, the authors organized their review thematically across the 57 studies. This method allowed them to show standard patterns in how stress develops in families and how it is affected by different types of support. By focusing on how family members relate to one another, the review offered practical insight into how stress moves throughout the whole household and changes over time.

A significant contribution of Meadan et al.'s (2010) review is its emphasis on bidirectional influence, how stress in one family member can affect others. For example, the stress experienced by a mother may impact her partner, which then may influence the child's behavior. This dynamic reflects the Family Systems Theory (Bowen, 1978; Minuchin, 1974), which explains how stress in one member inevitably affects the entire family system. The authors highlight how both formal (e.g., respite care, behavioral therapy) and informal (e.g., family, friends, community members) support systems play a significant role in reducing stress and improving family functioning. Families with more robust support networks reported lower stress levels, healthier relationships, and greater resilience. Conversely, families with limited support experienced more frequent conflict, decreased well-being, and burnout.

These findings support the idea that perceived support, when available and accessible to a family's specific structure and needs, can alleviate caregiver stress in meaningful ways. Other strengths of Meadan et al.'s (2010) review include its systems-level perspective, showing

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that stress rarely affects just one person in the family; rather, it spreads through relationships. The authors argued that family members can either protect or aggravate each other's anxiety, depending on the supports in place. Despite the challenges of raising a child with ASD, some families reported personal growth, increased empathy, and strengthened relationships. However, the review also had limitations that include the time frame of reviewed studies (2000-2007), which may exclude more recent data. Cultural diversity was limited, which makes it difficult to generalize results to families from non-Western or underserved populations.

Meadan et al. (2010) provide a strong conceptual framework for understanding how the presence or absence of support shapes the caregiving experience. They show why services must look at the whole family, not just one individual. When families receive support that fits their specific roles and relationships, such as parenting guidance, sibling support, or couples counseling, they are more likely to manage stress in healthy ways. This review helped shift the conversation away from parent blame or a singular focus on the child with ASD toward a better understanding of how family dynamics influence caregiver well-being.

To provide a deeper, firsthand account of caregiver challenges, Resch et al. (2010) conducted a qualitative study to explore the main challenges they face when raising a child with disabilities. These authors conducted seven focus groups with a total of 40 parents across multiple communities in a southwestern U.S. state. Each group included three to seven participants and was facilitated by a trained moderator using a semi-structured protocol. Researchers asked parents open-ended questions such as, "What are the biggest challenges you face?" and "What services have helped or not helped you?" to prompt honest responses based on experience.

Transcripts from each focus group were audio-recorded and entered into NVivo 7 qualitative software. Resch and colleagues (2010) used an iterative content analysis process of data reduction, data display, and conclusion drawing/verification recommended by Miles and

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Huberman (1994). A team of three researchers conducted coding using a multilayered approach. Their work created initial codes based on the interview guide and relevant literature, which they refined into broader superordinate categories. To ensure coding reliability, each transcript was reviewed by a primary and secondary coder, with a third team member resolving disagreements. Resch et al. (2010) validated themes through a cross-site comparison to ensure consistency across focus groups. To enhance credibility, they conducted a member-check process with parent representatives, who determined the accuracy of the results, interpretations, and conclusions based on the focus group participants' lived experiences.

Resch and colleagues (2010) identified four recurring themes: difficulty accessing information and services, financial stress, lack of school and community inclusion, and insufficient family support. These barriers reflect an ongoing discrepancy between what families need and what the environment offers. Parents described their roles within the community in complex ways, ranging from educators and advocates to individuals who felt pressured to hide or minimize aspects of their caregiving. These stories show that ableism and exclusion go beyond gaps in services. They described feeling overwhelmed, isolated, and ignored by systems that were supposed to help them.

The process of navigating fragmented services, often with unclear eligibility criteria or long waitlists, was frequently named as a source of emotional exhaustion. For example, one parent described the frustration of waiting more than 18 months for speech services, only to learn that eligibility criteria had changed. For families like this, the uncertainty becomes a daily emotional burden rather than just a simple delay. The study's findings support the idea that caregiver stress is not only due to the demands of the child's condition, but also to the failure of support systems to respond effectively. Resch et al. (2010) argued that such breakdowns lead caregivers to feel that they consistently overextend their emotional, financial, and logistical resources.

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The study's strengths lie in its real-world relevance and detailed insights. Giving a voice to parents' real-world experiences shows the emotional significance of navigating inadequate support structures. By carefully organizing and checking their coding process, Resch et al. (2010) were able to share participants' personal stories in a way that was meaningful and well-structured.

However, the study also had limitations. This study was limited to parents from a single U.S. state, which affects the applicability of its findings. Resch and colleagues (2010) did not include ethnic minorities such as Asian Americans and Native Americans in the sample due to their small percentage of the state's population. Additionally, two to three invited participants per focus group did not attend, which may have limited the diversity of perspectives represented. Another limitation is that 90% of participants were women, which may not reflect the experiences of male caregivers. Finally, the use of a single data collection method (focus groups) may have captured only part of the actual parent experience. Despite those shortcomings, the study added context to the broader conversation by showing what stress looks like at the ground level.

Waqar et al. (2024) conducted a quantitative cross-sectional study examining the predictors of caregiver stress among 200 caregivers in two cities in Punjab, Pakistan. The researchers used convenience sampling, identifying participants through schools and centers serving children with developmental disorders. The study's purpose was to determine how sociodemographic factors such as family income, parental education, number of children, and time since diagnosis shape caregiver stress. Using the Perceived Stress Scale (PSS-10) and regression analysis, the authors found that lower income, fewer years of education, more children, and less time since the child's diagnosis were significantly associated with higher stress levels. The PSS-10 is a 10-item instrument that measures the degree to which an individual perceives a situation as stressful (Cohen & Williamson, 1988; Lee, 2012). The mean

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PSS-10 score among participants was 31.9 (SD = 2.42), indicating moderate to high stress, with 81.5% of caregivers falling into moderate to severe stress categories. These results were statistically significant and consistent with the general literature identifying struggles of caregivers in areas with limited support or services.

The strength of this study lies in its situational focus. By focusing on caregivers in a non-Western, underrepresented population, Waqar et al. (2024) helped fill a gap in the research by showing how low income, caregiving responsibilities, and limited access to services affect stress levels in that area. Their findings reinforce the understanding that environmental and socioeconomic variables shape stress, and that perceived support or its absence is deeply connected. Additionally, the sample size was appropriate, and the tools used were valid and reliable.

There were also limitations, including the use of convenience sampling, self-report bias, and the absence of longitudinal tracking to observe changes in stress over time. This research is especially relevant to this capstone because it affirms that without adequate support, the pressures caregivers face can seriously harm their well-being.

While Meadan (2010) and Resch (2010) examined systemic and personal aspects of caregiver stress, Waqar et al. (2024) highlighted how sociodemographic factors predict elevated stress in under-resourced settings. Rivard et al. (2014) focused on specific factors that predict parental stress in measurable ways. In their study, 118 mother-father dyads of preschool-aged children (2-5 years old) with autism in Quebec, Canada, were assessed to determine how variables such as child adaptive functioning, service wait times, and socioeconomic status affect stress levels.

To measure these variables, Rivard and colleagues (2014) used the Parenting Stress Index-Short Form (PSI-SF) and standardized developmental assessments, including the Childhood Autism Rating Scale (CARS) to evaluate autism symptom severity, the Wechsler

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Preschool and Primary Scale of Intelligence (WPPSI-III) to measure cognitive functioning, and the Adaptive Behavior System-II (ABAS-II) to assess adaptive skills. The authors conducted hierarchical regression analyses, a statistical approach that adds predictors in steps (e.g., demographic variables first, then child characteristics, then family-context variables) to evaluate how different factors contribute to caregiver stress.

Their final model revealed that lower adaptive functioning in children and longer wait times for services were key predictors of heightened stress for both mothers and fathers. Interestingly, fathers reported even higher stress levels than mothers, challenging the common assumption that mothers consistently shoulder the greater emotional weight. For mothers, stress was closely tied to the child's intellectual ability and adaptive functioning. For fathers, stress was more strongly influenced by autism symptom severity and adaptive skills. Rivard et al. (2014) suggest that different child characteristics affect each parent in different ways. Additionally, families with fewer resources and weaker informal support systems experienced greater distress overall.

Rivard et al.'s (2014) findings are consistent with the conclusions of Gallagher et al. (1983) nearly 30 years before, which identified child characteristics such as adaptive functioning and socioeconomic pressures as key predictors of parental stress. Also consistent with Gallagher et al.'s conclusion that limited resources and support systems greatly contributed to elevated levels of distress, Rivard et al. observed that weaker informal supports and longer service wait times significantly contributed to heightened caregiver burden. These findings highlighted the urgency of providing timely, inclusive, and family-centered interventions that address the unique stressors experienced by both parents.

Rivard et al.'s (2014) study is strengthened by the inclusion of both parents and by using a range of validated tools to measure child development and caregiver stress. The researchers also ensured consistency in the timing of assessments by measuring stress before families

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began early intensive behavioral intervention, providing a picture of baseline stress. It also included straightforward implementation of variables such as the child's adaptive functioning (measured by the ABAS-II), intellectual ability (measured by the WPPSI-III), and autism symptom severity (measured by the CARS), as well as contextual factors like wait times for services and maternal educational level. The inclusion of modifiable factors such as service delays and access to support strengthens the study's real-world application to policy and practice. Despite its strengths, as a cross-sectional study, it cannot establish causal relationships, and excluding single-parent families may limit broader relevance. However, the study offers important insights into how service delivery and support systems influence caregiver well-being.

Summary of Findings for RQ1: The Relationship Between Stress and Support

Together, these articles present the wide range of challenges caregivers face, from emotional strain and social isolation to unmet service needs. They explain the complex relationship between caregiver stress and perceived support, providing clarity that directly addresses the capstone's first research question. Each one contributes a unique perspective as to how the presence or absence of supportive factors in families of children with ASD shapes stress. These five investigations provide a comprehensive picture of how stress and support in the lives of caregivers raising children with ASD are connected. Hayes and Watson (2013) established that these caregivers experience significantly more stress than other parent groups. Meadan et al. (2010) explained how stress flows and is shaped through family systems by the presence or absence of support. Resch et al. (2010) gave voice to caregivers navigating inadequate service environments; Waqar et al. (2024) emphasized how factors like income, education, and family size contribute to elevated stress; and Rivard et al. (2014) identified measurable predictors of stress, including service delays and low adaptive functioning.

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While each study offers valuable insights, several lacked cultural diversity or long-term data, leaving questions about how support needs vary across caregiver populations and change throughout the caregiving journey. These limitations reveal the need for more inclusive and sustained research that shows the diversity of caregiver experiences and the progression of stress over time.

RQ 2: Which types of support -- emotional, informational, or instrumental -- are most associated with reduced caregiver stress?

While Rivard et al. (2014) emphasized systemic predictors of stress, including child functioning, socioeconomic status, and delayed access to services, the next set of studies explored what types of interventions can help reduce that stress. One such intervention is respite care, a service designed to provide temporary relief for caregivers. In the literature, respite care is often categorized as a form of instrumental support, a practical resource that directly reduces the daily demands of caregiving while creating space for parents to recover (Meadan et al., 2010; Resch et al., 2010). Christi et al. (2022) examined the effectiveness of respite care in military families of children with autism, giving insight into how targeted support can improve mental health outcomes for caregivers who often face additional levels of instability and stress.

Christi and colleagues (2022) examined the effectiveness of respite care and its influence on caregiver mental health in military families. They conducted a quantitative, cross-sectional pilot study to assess the effects of respite care on stress, anxiety, and depression among 119 active-duty military parents enrolled in the Exceptional Family Member Program (EFMP). EFMP is a required Department of Defense program that assists military families with members who have special medical or educational needs. It ensures their needs are considered in duty assignment decisions and provides access to comprehensive services in community, education, medical, housing, and personnel-related matters (Department of Defense Instruction

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1315.19, 2023). Participants recruited from clinics and by email completed three surveys anonymously. Mental health outcomes were measured using two validated screening tools, the PSS-10 and the Patient Health Questionnaire-4 (PHQ-4) (Kroenke et al., 2009; Löwe et al., 2010). The PHQ-4 is a brief screening tool composed of four items that assess symptoms of anxiety and depression.

Statistical analyses, including chi-square tests and multivariate ordinal logistic regression, were used to examine relationships between access to respite care and mental health outcomes. The chi-square tests determined whether there were statistically significant differences in respite care access based on categories such as military rank, duty station, and the presence of comorbid conditions in the child. Christi et al. (2022) identified patterns of disparity across different groups. The multivariate ordinal logistic regression allowed for a more detailed analysis by evaluating how multiple variables predicted the likelihood of varying levels of stress, anxiety, and depression.

In Christi et al.'s (2022) study, the mean PSS-10 score was 17.58 (SD = 8.038) and the mean PHQ-4 score was 4.14 (SD = 3.076), revealing moderate stress and mild to moderate symptoms of anxiety and depression among participants. Parents with access to respite care reported significantly reduced stress and mental health symptoms with lower PHQ-4 scores ($p = .017$) and lower PSS-10 scores ($p = .016$). Elevated distress was significantly associated with parental history of anxiety or depression ($p < .001$) and with having a child who had comorbid conditions like attention deficit hyperactivity disorder (ADHD), anxiety disorder, depression or mood disorder, genetic or chromosomal disorder, sleep disorder or insomnia, global developmental delay, intellectual disability, and specific learning disabilities. Despite experiencing greater caregiving demands, these families were less likely to access respite care (PHQ-4: $p = .01$; PSS-10: $p = .001$).

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Several factors may explain Christi and colleagues's (2022) findings. Children with complex needs often require specialized care, making it hard for families to rely on typical options like babysitters or daycare. Access to respite care also varies by military rank, education level, and location, with fewer services in some areas. Changing duty stations can also produce added challenges, such as losing access to Medicaid-based respite programs that don't transfer between states. Additionally, inconsistencies in EFMP implementation, especially in areas like standardized policy, program oversight, and equitable resource distribution across branches, further limit access. In some cases, parents may not know about available services or may feel uncomfortable asking for help. These issues make it harder for families who need support the most to receive it.

A strength of Christi et al.'s (2022) study is its use of psychological tools (PHQ-4 and PSS-10) with established reliability and validity to measure caregiver outcomes. Additionally, the study is one of the first to quantitatively assess the effects of respite care specifically within the military, which is an under-researched population with unique stressors like relocations and deployments. The use of chi-square tests and multivariate ordinal logistic regression strengthened the analysis by identifying and adjusting for variables like rank, education level, and comorbidities.

The limitations include a restricted sample size ($n = 119$), which limits the generalizability of the results and demonstrates the need for larger-scale research to validate the findings. Additionally, a low response rate (19.8%) introduces the possibility of selection bias, mainly since many participants were recruited through EFMP and already seeking support due to elevated stress levels. The study also relied on self-report data and did not include a control group or pilot-test the surveys, which limit causal conclusions and may introduce reporting bias. Finally, nearly 29% of the participants were unable to report the severity of their child's autism, which limited the analysis of how severity affects mental health outcomes. Despite these

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limitations, the findings show compelling support for integrating respite care into military family health initiatives. Respite care is a crucial component in maintaining caregiver mental health. Christi et al. (2022) emphasized the need for more consistent communication and outreach about available respite care services.

While Christi et al. (2022) demonstrated that respite care can significantly reduce stress and improve mental health for military families, their work also revealed gaps in service access, especially for families with more complex needs. These findings highlight a broader issue across caregiver support systems, as interventions must be available and tailored to the unique cultural, linguistic, and contextual realities of the families they serve.

The following study explored how culturally responsive parent education programs can effectively address caregiver stress by aligning content and delivery with families' values, communication styles, and lived experiences.

While respite care proved to be a powerful intervention, culturally specific education programs also offer unique benefits, as demonstrated in the work of Chiang (2014). The author evaluated a culturally responsive, group-based parent education program aimed at reducing stress and enhancing confidence among Chinese-American parents of children with ASD. The study used a pre-experimental, one-group pretest-posttest design involving 11 parents in a 10-week program delivered in Mandarin, Cantonese, and English. The sessions included lectures, role plays, group discussions, and peer support tailored to cultural expectations around family harmony and saving face, which shows the importance of maintaining dignity and avoiding stigma in many Chinese families.

Parenting stress was measured using the PSI. The Confidence Degree Questions (CDQ), a short questionnaire that evaluates an individual's perceived ability to manage caregiving responsibilities, was used to calculate parental confidence. Quality of life was measured using the World Health Organization Quality of Life-Brief Version (WHOQOL-BREF).

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The WHOQOL-BREF is a 26-item questionnaire that assesses an individual's quality of life by measuring four domains: physical health, psychological well-being, social relationships, and environment (WHOQOL GROUP, 1998). In both the parent and child domains ($z = -2.02$, $p < .05$), considerable reductions in stress were observed. Parental confidence also increased significantly post-intervention ($z = 2.02$, $p < .05$), indicating that culturally adapted content and delivery methods can directly improve mental health and coping.

Chiang's (2013) study addressed overlooked cultural factors that shape caregiver stress in immigrant communities. One of the study's strengths was its culturally designed approach, offering the parent education program in Mandarin, Cantonese, and English and incorporating values like family harmony and saving face. Another strength was the use of validated tools such as PSI, CDQ, and WHOQOL-BREF, which gave credibility to the study. The incorporation of role-play, peer discussion, and group-based delivery also increased the program's cultural and social validity.

Despite these strengths, the study had limitations. The small sample size and lack of a control group limit generalizability. Additionally, the short follow-up period leaves it unclear whether participants sustained the improvements over time. Regardless, Chiang's (2013) study supported the idea that cultural relevance enhances both engagement and outcomes in caregiver programming. It also added to a growing body of evidence calling for ethnically inclusive models of support. The researcher demonstrated the value of culturally adapted education programs in reducing stress and increasing confidence among Chinese-American parents, similar to efforts in other underrepresented populations.

Al-Khalaf et al. (2013) furthered work in this area by designing a brief, psychoeducational program for Jordanian mothers of children with ASD. These authors conducted a pre-experimental, one-group pretest-posttest study to assess the effectiveness of a four-session psychoeducational program designed to reduce maternal stress and improve

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copied among the participants. The researchers also compared maternal and paternal outcomes, offering a more comprehensive view of family-level impacts. The sample consisted of 10 mother-father dyads ($n = 20$ participants) recruited from two private special education centers in Amman using purposive sampling based on enrollment and parental willingness to participate.

Al-Khalaf and colleagues (2013) conducted the study in three phases. In the first phase, both mothers and fathers completed the Parental Stress Index (PSI), which measured the frequency and intensity of parenting stress, and the Coping Strategy Indicator (CSI), which addressed their use of problem-solving, social support, and avoidance strategies. The researchers used these instruments to establish baseline levels of stress and coping. Mothers also participated in semi-structured, audio-recorded interviews designed to study their perceptions of disability, their child's diagnosis, the emotional challenges they faced, and the types of support they found helpful or lacking. The interviews provided detailed qualitative data on the personal and cultural conditions of caregiving in Jordan. Fathers were not interviewed but completed the surveys.

In the second phase, mothers participated in a four-session psychoeducational program delivered over four weekly sessions. The curriculum covered ASD education, stress management, behavior support strategies, and emotional resilience techniques. The sessions aimed to increase autism knowledge, improve coping, and provide practical strategies for managing both child behavior and maternal stress. To ensure linguistic and cultural appropriateness, the PSI and CSI were translated into Arabic and reviewed by a bilingual doctoral student to maintain validity in non-Western contexts. Al-Khalaf et al. (2013) conducted pre- and post-intervention assessments using the PSI, which for this study demonstrated high internal consistency ($\alpha = .83 - .92$), and the CSI, which also showed high reliability ($\alpha = .88 - .91$).

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In the third phase, mothers completed both instruments again and participated in a follow-up interview conducted by an independent interviewer to reduce bias. This strategy enabled Al-Khalaf and colleagues (2013) to compare pre- and post-intervention scores and assess perceived changes in coping and stress.

Al-Khalaf et al. (2013) reported statistically significant reductions in maternal stress and increases in coping scores after the intervention. Specifically, the mean total stress score on the PSI decreased from 139.4 to 98.2, showing a change from high to moderate stress levels. Simultaneously, the mean total coping score on the CSI increased from 53.7 to 82.6, indicating that mothers reported greater use of effective coping strategies, especially problem-solving and social support, after participating in the program. The design featured no control group and had a small sample size, which limited the ability to generalize the findings or establish causality. However, the internal improvements from pre- to post-intervention were interesting because of the cultural stigma around autism and the lack of caregiver resources in Jordan.

The study's strengths include the use of validated and reliable instruments. Al-Khalaf et al. (2013) advocated for the widespread implementation of brief, cost-effective programs in under-resourced communities where caregivers may have limited access to formal psychological services. The findings highlighted how modest interventions can significantly improve caregiver well-being and resilience. While these culturally responsive programs demonstrate the value of tailoring education to family needs, other researchers have examined how technology can further expand access to those supports.

Banbury et al. (2018) conducted a systematic review of 17 studies to evaluate the feasibility, acceptability, effectiveness, and implementation of telehealth group videoconferencing interventions delivered into participants' homes. The review found strong evidence that videoconferencing groups were feasible and acceptable, with all 17 studies reporting high participation satisfaction and most showing completion rates above 70%. Across

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studies, caregivers described reduced feelings of isolation, increased social connectedness, and improved health literacy. For example, participants valued “meeting new people in similar circumstances” without needing to travel, which directly addressed common barriers such as distance and mobility (Banbury et al., 2018, p. 8). These consistent findings show that videoconferencing can replicate many of the relational and information benefits of face-to-face groups.

However, the review also identified key weaknesses. The heterogeneity of study designs and measures prevented meta-analysis, limiting conclusions to descriptive synthesis. The majority of studies were small-scale pilots, with sample sizes often fewer than 30 participants, raising concerns about generalizability. Evidence of long-term outcomes was limited; only three studies included follow-up beyond program completion, and results were mixed. Most interventions did not examine cultural or linguistic differences in accessibility, leaving questions about equity for diverse caregiver populations. Despite these limitations, Banbury et al. (2018) demonstrated that videoconferencing support groups can reduce isolation and improve access to peer connections, especially for individuals who face geographic or mobility barriers. Their work emphasized accessibility and feasibility, rather than cultural context.

Adding to this culturally grounded research, Wakimizu and Fujioka’s (2024) qualitative study in Japan was included because it provides insights into how cultural context forms caregivers’ perceptions of support needs. The authors conducted a cross-sectional survey, using open-ended, self-administered questionnaires distributed through 89 special-needs schools registered with the National Federation of Parent-Teacher Associations. They collected responses from 1,173 caregivers (704 primary caregivers and 469 spouses). Most of the respondents were mothers in their 40s. Although the study focused on caregivers of children with severe motor and intellectual disabilities (SMID) rather than ASD, its findings were still relevant because they show how cultural factors affect support needs.

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Wakimizu and Fujioka (2024) prompted participants to describe the kinds of social support they needed for caregiving in both home and community settings. The researchers identified themes using Krippendorff's content analysis method. This method requires researchers to systematically code textual data to uncover patterns, themes, and meaning while maintaining transparency and reliability (Krippendorff, 2018). It is a structured way of analyzing what people say so that researchers can identify recurring ideas and ensure the results are consistent and trustworthy. Two graduate-level researchers served as coders to independently review the data, then discussed their interpretations to reach consensus. To strengthen credibility, they conducted a member-checking process with parent representatives.

The analysis produced seven major categories, 27 subcategories, and 79 codes, identifying three main types of support: emotional reassurance, clear and timely information, and opportunities for peer connection. Participants reported feeling less isolated and more capable when they could talk to others with similar experiences, receive guidance from professionals in plain language, and have their emotions acknowledged and validated. Many caregivers noted that peer relationships often reduced stress more than clinical services, especially when professional interactions felt cold, rushed, or impersonal. Wakimizu and Fujioka (2024) also highlighted how cultural values such as self-restraint, endurance, and fear of judgment determined whether caregivers sought help, suggesting that providers must offer support in ways that feel emotionally safe and culturally appropriate.

Although emotional support, clear information, and peer connection were the most common needs, the authors also found that caregivers needed help in home life, school settings, medical care, and community interaction. These findings demonstrate that support must be available in all parts of a caregiver's life to be effective. Spouses, who made up nearly 40 percent of participants, often shared the same concerns as primary caregivers, showing that both parents experience similar emotional stress. Wakimizu and Fujioka (2024) also noted that

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support must be proactive, as many caregivers hesitate to seek help due to internalized pressure to handle situations on their own. These findings emphasize that building trust and accessibility is just as critical as the services offered.

Like Dunst and Trivette (2009), Wakimizu and Fujioka (2024) stressed that families benefit most when treated like partners in the care process. Despite limitations, such as written responses rather than interviews and the exclusion of children without SMID, the study provided a wide-reaching national sample. Its findings promote the idea that caregiver support programs should prioritize emotional trust, shared experience, and accessible communication, especially for families who may delay expressing their needs due to stigma or cultural norms. This research helps fill a significant gap by sharing the views of caregivers in a less-studied, non-Western country. It offers valuable guidance for creating support programs that are more inclusive and effective.

Summary of Findings for RQ2: Types of Support and Reduced Stress

The five studies reviewed in this section demonstrate that support works best when it is based on substantial evidence and matches the real-life needs, values, and cultures of the families receiving it. Christi et al. (2022) showed that respite care plays a critical role in alleviating stress, anxiety, and depression among military caregivers, especially when access is consistent and equitable. Chiang (2014) and Al-Khalaf et al. (2013) demonstrated how culturally tailored education and support reduce stress and build confidence and resilience among caregivers. Banbury et al. (2018) extended these findings by showing that videoconferencing groups can reduce isolation, improve health literacy, and provide accessible support that overcomes barriers of distance and mobility. Wakimizu and Fujioka (2024) added to this understanding by showing that emotional reassurance, peer connection, and clear communication are vital in cultures where stigma or social pressure may keep caregivers from asking for help. Whether through structured respite, brief psychoeducation, or emotionally

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validating peer support, the research emphasizes that adequate caregiver support must be accessible, relevant, and responsive to the unique demands of each community. These findings reinforce the importance of designing interventions that respect cultural context and the realities of families raising children with ASD. While these studies identify forms of support that reduce stress, it is essential to understand what makes such programs successful. The following section addresses the third research question and investigates design principles such as cultural responsiveness, peer delivery, and stigma reduction that determine effective caregiver interventions.

RQ 3: What key characteristics of social support programs do caregivers identify as most beneficial in coping with stress?

While understanding the historical roots of stigma and the predictors of caregiver stress provides critical insight into the challenges faced by parents and caregivers of children with autism, it is equally crucial to examine the programs and interventions designed to support them. Extending the contributions of the earlier discussions of caregiver stress and systemic barriers, this section explores the key characteristics that make social support programs effective, sustainable, and meaningful for families raising children with ASD.

Recent research has gone beyond recording caregiver hardship to identifying strategies that promote resilience, emotional wellness, and social connection (Dykens et al., 2014; Frantz et al., 2017; Lodder et al., 2020). The following studies focused on structured interventions like mindfulness training and positive psychology approaches (Dykens et al., 2014; Frantz et al., 2017), stigma reduction programs (Lodder et al., 2020), peer-to-peer mentorship models (Damianakis et al., 2016; Lee et al., 2023), family-centered service frameworks (Russa et al., 2014), and strategies for addressing internalized stigma (Yanos et al., 2015). Collectively, they identified recommendations for developing culturally responsive, accessible, and emotionally nurturing support systems that are designed to sustain caregiver well-being over time.

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Frantz et al. (2017) conducted a systematic literature review of 41 studies examining the effectiveness of various interventions aimed at improving caregiver well-being for parents of children with ASD. The 41 studies in the review included a total of 2,147 parents, predominantly White/Caucasian mothers. The types of interventions evaluated included psychoeducation, cognitive behavioral therapy (CBT), mindfulness-based stress reduction (MBSR), and behaviorally based programs. Data were collected using coding sheets to capture details regarding participant characteristics, intervention types, outcome measures, and methodological quality. The researchers demonstrated credibility through a systematic and transparent coding process that included multiple reviewers, with inter-rater reliability ranging from 89.4% to 93%. The review followed the quality standards of the What Works Clearinghouse (WWC, 2020) and included independent coding and high inter-rater agreement.

Frantz and colleagues (2017) concluded that mindfulness-based and behavioral interventions yielded the most consistent improvements in caregiver stress, anxiety, and psychological health. Key findings showed that successful interventions were mostly group-based, had built-in opportunities for caregiver reflection and social support, and emphasized caregiver well-being as the primary outcome over child-focused interventions.

The authors identified several limitations in these studies, including an overabundance of quasi-experimental studies (71.43%), limited reporting on treatment fidelity, and a lack of diversity among participants. Despite these limitations, the findings suggest that caregiver-specific interventions that promote emotional connection, skill development, and self-care lead to measurable mental health benefits. Frantz et al. (2017) noted the need for further research on long-term effectiveness and accessibility, especially for underserved caregiver populations.

To complement this intervention-focused perspective, Riley and White (2016) explored how individuals develop a sense of belonging when surrounded by peers who understand and share similar lived experiences. Although their study focused on gifted education rather than

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ASD, it was included because it highlights how belonging and peer affirmation shape the effectiveness of support programs. Those insights are directly transferable to caregivers of children with disabilities. While their study focused on students identified as gifted, as well as their parents and teachers, the findings offer valuable insights into the emotional and relational qualities that can make support programs more meaningful, especially for caregivers of children with disabilities, who often struggle to find acceptance and understanding in normal settings.

The researchers used a qualitative, interpretive phenomenological design to better understand the experience of belonging in peer-based learning environments. The study centered on the idea that belonging is about more than feeling comfortable; it is a fairness issue that influences access to opportunity, voice, and emotional well-being. Riley and White (2016) acknowledged their positionality as educators and advocates for gifted learners, which helped frame their interpretations while also recognizing transparency about their biases.

The sample included 24 participants: 10 students (ages 10-13), 10 parents, and four teachers. All participants were affiliated with gifted education programs in Auckland, New Zealand, and selected through purposeful sampling. They had direct experience with enrichment programs intended to connect like-minded learners and promote intellectual and emotional engagement. The setting included a variety of enrichment environments, including cluster classes, withdrawal programs, and Saturday extension groups.

Riley and White (2016) collected data through semi-structured interviews, which were conducted in person or by phone. Interviews were audio-recorded and transcribed. The authors employed thematic analysis, organizing the data into codes and emerging themes. They followed a structured process of reading, re-reading, and coding, as well as identifying and refining themes to ensure that the analysis remained grounded in participant experiences.

Three major themes emerged from the data: (1) Belonging as emotional safety and freedom, where participants expressed feeling emotionally at ease in these peer-aligned

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spaces; (2) The power of shared identity where both students and parents described the comfort of being with others who “just got it;” (3) Belonging as a matter of equity where the authors emphasized that the ability to access peer-aligned environments should not be a privilege, but a necessary condition for meaningful learning and emotional growth.

Riley and White’s (2016) findings demonstrated that emotional validation and shared understanding were among the most valued aspects of the program experience. For parents, being in a space where they did not have to constantly explain or defend their child was most affirming. These feelings reflect the kinds of emotional burdens caregivers of children with autism often carry, especially in environments where their experiences are misunderstood or dismissed.

Riley and White (2016) enhanced the trustworthiness of their study by using multiple stakeholders--students, parents, and teachers--which added depth and triangulation. They also supported their findings with vivid participant quotes, giving voice to their subjects’ emotional experiences. Although the authors did not explicitly mention intercoder agreement or member checking, their coding process indicated the credibility of their interpretations.

There are limitations in the research. First, this small-scale study involved 10 students, their parents, and teachers, all of whom volunteered to participate, were active in a gifted program, and may have held biased views due to like-mindedness. Another limitation is it focused on a specific educational group, gifted enrichment programs. Finally, the study excluded detailed demographic information such as ethnicity or socioeconomic status, which limits the transferability of findings to more diverse or marginalized caregiver populations.

Despite the limitations, the implications clearly show that support programs are most effective when they promote a sense of belonging. For caregivers, especially those who feel excluded or judged in other areas of life, being in a space where they feel emotionally safe and seen can be just as important as any curriculum or intervention. Riley and White’s (2016) study

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reinforced the value of shared identity, peer affirmation, and emotional safety as key characteristics of high-quality support environments.

Extending the emotional themes emphasized by Riley and White (2016), Dykens et al. (2014) conducted a randomized controlled trial to explore how brief, peer-led interventions, Mindfulness-Based Stress Reduction (MBSR) and Positive Adult Development (PAD), influence caregiver resilience and emotional recovery. MBSR is a structured program that teaches participants to manage stress through mindfulness practices such as focused breathing, meditation, and emotional regulation (Kabat-Zinn, 1990). PAD incorporates principles of positive psychology that encourage resilience, meaning, and well-being (Seligman, 2011). Trained peer mentors delivered both through six weekly group sessions. The researchers compared the effects of these two programs on stress, anxiety, depression, sleep quality, and life satisfaction among 243 mothers of children with neurodevelopmental disabilities, 65% of whom had children with autism. Both programs are grounded in established theoretical frameworks, MBSR in mindfulness-based stress reduction (Kabat-Zinn, 1990) and PAD in positive psychology (Seligman, 2011). These theories shaped the creation of the interventions to reduce stress, improve emotional regulation, and strengthen caregivers' sense of identity.

Dykens and colleagues (2014) collected data at six time points and analyzed them using mixed random-effects models. They used validated psychological instruments to measure all outcomes, which strengthened the reliability of their findings. Both groups showed statistically significant improvements across all measures. MBSR was more effective at reducing anxiety, depression, and sleep disturbance in the short term (Cohen's $d = 0.88-1.10$), while PAD resulted in greater long-term gains in life satisfaction and emotional well-being. The results were significant at both the $p < .05$ and $p < .01$ levels.

Dykens et al. (2014) emphasized the accessibility, affordability, and overall effectiveness of peer-led interventions. By training caregivers to serve as facilitators, these programs used

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lived experiences as a therapeutic advantage. The study's high participant retention and consistent outcomes support the idea that brief, skills-based, peer-delivered programs can generate lasting mental health benefits for caregivers under chronic stress.

While Dykens et al. (2014) emphasized emotional well-being, Lodder et al. (2020) shifted the focus to stigma reduction through the *Stigma of Living as an Autism Carer* (SOLACE) program, an eight-week group-based intervention for parents of recently diagnosed children with autism. Their work was informed by Corrigan & Watson's (2002) 3A model of self-stigma. The model describes the process of becoming aware of stereotypes, agreeing with them, and applying them to oneself. SOLACE integrated cognitive-behavioral strategies through group sessions and guided activities to help caregivers confront negative beliefs and strengthen their sense of identity.

This mixed methods randomized controlled trial (RCT) included 17 parents assigned to either the SOLACE intervention group or a waitlist control group. Lodder et al. (2020) assessed outcomes at three time points: baseline, post-intervention, and six-week follow-up. Key outcome measures included self-esteem, stigma, loneliness, mental health, and caregiving satisfaction. The researchers used validated tools, including the Mental Health Inventory-5 (MHI-5) for psychological well-being, the Affiliate Stigma Scale, and the Rosenberg Self-Esteem Scale. They used t-tests (to compare differences between the intervention and control groups), ANOVAs (to analyze changes across the three time points), and intention-to-treat analysis, which includes all participants regardless of drop-out, to ensure the groups remained balanced and objective.

Participants showed statistically significant improvements in several domains, including mental health ($p = .034$), self-esteem ($p = .002$), and positive meaning in caregiving ($p = .01$). Stigma directed to those closely affiliated with a stigmatized individual, or courtesy stigma, decreased significantly ($p = .03$). Participants reported increased social connection and reduced

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loneliness ($p = .01$). Lodder and colleagues (2020) used validated tools to measure each outcome, with internal consistency values (Cronbach's alpha) ranging from .75 to .95, supporting the reliability of the measures.

The study demonstrated that SOLACE is both feasible and effective in reducing stigma among caregivers. The strengths include the safe, peer-led environment, and the combination of cognitive reframing, narrative sharing, and identity reconstruction empowered participants. Lodder et al. (2020) argued that reducing stigma is a key part of any program aimed at improving caregiver well-being.

While Lodder et al. (2020) showed the SOLACE program could help reduce stigma and improve caregiver well-being, there are some major limitations to consider. The study included a small number of participants, which makes it challenging to apply the findings to a larger, more diverse group. Most participants were mothers from similar backgrounds, so the results might not reflect the experiences of all caregivers. The short follow-up period also makes it uncertain whether the improvements lasted over time. Even with these limitations, the program's use of strategies like cognitive reframing and storytelling, based on a clear stigma framework, adds value to the development of future caregiver support programs.

Continuing the theme of relational and emotional support, Lee et al. (2023) drew attention to the role of peer-to-peer mentorship as a scalable solution for caregiver needs. The authors conducted a scoping review of 25 empirical studies evaluating peer-to-peer (P2P) support programs for parents of children with autism. Lee et al. categorized these programs into structured group sessions and one-on-one mentorship models. The reviewed studies included 141 trained parent mentors and 747 mentees, representing diverse cultural and socioeconomic backgrounds.

Lee and colleagues (2023) identified multiple benefits associated with P2P programming, including parental self-efficacy, reduced isolation, improved coping strategies,

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and greater emotional resilience. Studies in underserved or marginalized communities had the greatest benefits, suggesting P2P support helps when formal services are overloaded or hard to access. Cascading mentorship models, where trained caregivers mentor others, were especially useful for reaching underserved populations.

Lee et al.'s (2023) review also pointed out considerable variation in program design, length, and mentor training procedures. While all programs emphasized lived experience and relational support, many lacked clearly defined theoretical frameworks or long-term evaluation data. This gap raises questions about the sustainability of their outcomes. Without a guiding framework, it may also be more difficult to replicate or scale these programs across different caregiver populations.

Despite these limitations, Lee et al. (2023) concluded that P2P models demonstrate high social validity and represent a scalable, culturally adaptable strategy for caregiver support. While Lee et al. highlighted the benefits of in-person P2P mentorship, Damianakis et al. (2016) explored how these same dynamics could be created in an online environment.

Damianakis et al. (2016) conducted a qualitative study evaluating a 10-week web-based video support group for 10 caregivers of individuals with traumatic brain injury (TBI) (non-ASD caregiving context, same factors apply). Although their study focused on caregivers of individuals with TBI, it was included because the psychosocial factors of stress, isolation, and peer validation are directly comparable to those experienced by caregivers of children with ASD. The program combined educational resources, discussion forums, and weekly clinician-facilitated videoconferences. Thematic analysis of the sessions revealed that participants consistently valued the group for helping them manage emotional stress and reduce feelings of isolation. Caregivers described the program as a lifeline, noting that it provided a safe space to express grief, share coping strategies, and receive validation from peers in similar situations. The study also found that participants reported increased confidence and competence in their

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caregiving roles, showing the potential of online programs to deliver meaningful psychosocial benefits.

While valuable, the study has important limitations. The small sample size ($n = 10$) and limited demographic diversity, primarily mothers from Ontario, Canada, restrict generalizability. The intervention lasted only 10 weeks, leaving scarce evidence of long-term sustainability. Additionally, while emotional improvements were clearly described, the reliance on qualitative data alone without standardized stress or burden measures limited comparability with other interventions. Questions remain about scalability, given the different levels of comfort with technology of caregivers and the resources required for professional facilitation. Despite these limitations, Damianakis et al. (2016) demonstrated that structured online support groups can meaningfully reduce isolation and validate caregiver experiences, offering another path for expanding caregiver access to peer support.

In contrast to intervention-specific studies, Russa et al. (2014) provided a systems-level framework for integrating family-centered principles into broader service delivery models. Rather than examining a specific intervention, they presented a conceptual framework and recommendations rooted in evidence-based practices, aimed at helping professionals and educators build family-centered systems of care. The authors drew from research and clinical experience, proposing that effective support models must include family-school collaboration, psychoeducation, consistent access to services, and early intervention across a child's development. Although this paper is not an empirical study, it integrated findings from previous research and professional standards to highlight practical models for expanding supports.

Russa et al. (2014) addressed barriers often faced by caregivers, such as limited school-based services, a lack of coordination between professionals, and cultural insensitivity. They outlined guiding principles for program development, including empowering parents through training and advocacy, reducing stigma, and promoting community inclusion. One of the most

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valuable contributions of this paper is the appeal for integration, connecting emotional, behavioral, and educational resources into a coordinated support network. The authors emphasized that the program's success lies in family partnership, flexibility, and follow-through by systems of care. Their work provides a critical framework for long-term sustainability and system-level change.

Building on this external systems view, Yanos et al. (2015) turned the focus inward to examine psychological strategies for reducing internalized stigma. They conducted a comprehensive narrative review of six structured interventions designed to reduce mental health self-stigma. Although this review focused on individuals with psychiatric diagnoses, the mechanisms and strategies discussed are relevant for caregivers of children with autism, many of whom experience internalized shame and self-blame associated with their child's diagnosis. The authors aimed to synthesize and compare program features to determine which approaches were most beneficial across varied populations and contexts.

Although this was not a formal systematic review, the authors employed a well-defined methodology. They conducted a database search using PsycINFO and Medline with terms such as "self-stigma," "internalized stigma," and "psychosis," combined with diagnostic terms like "schizophrenia" and "psychiatric disability." Inclusion criteria required interventions to specifically target negative self-beliefs related to severe mental illness, and the authors excluded those that focused solely on perceived stigma or addressed diagnoses not relevant to mental illness. The researchers organized the selected studies thematically and categorized them over multiple variables, including theoretical foundation, group format, number of sessions, facilitator type (peer vs. professional), mechanisms of action, and empirical support. Yanos et al. (2015) presented these findings in a matrix, which helped them compare the programs and relative strengths of each intervention.

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Yanos et al. (2015) included interventions that implemented psychoeducation: cognitive restructuring, a therapeutic technique for identifying and challenging negative thought patterns; narrative enhancement, which supports individuals in reframing and strengthening personal stories to promote empowerment and meaning; and photovoice methodology, a participatory approach that uses photography to facilitate reflection and advocacy. These programs used well-known psychological techniques, including cognitive-behavioral theory, narrative therapy, and participatory action research. These approaches aimed to help participants feel more empowered, build their self-esteem, and share their stories in supportive settings.

The authors found that programs combining both cognitive restructuring and narrative enhancements, such as Narrative Enhancement and Cognitive Therapy and Coming Out Proud, had the greatest impact on reducing internalized stigma and enhancing self-esteem and social engagement. Specifically, Yanos et al. (2015) described several intervention models that demonstrate how structured programming can transform internalized stigma into empowerment.

Narrative Enhancement and Cognitive Therapy (NECT) is a 20-session, group-based intervention that integrates psychoeducation, cognitive restructuring, and narrative therapy. Participants first learn to identify and challenge self-stigmatizing thoughts and beliefs through cognitive techniques, then move into guided storytelling and reflection. The narrative enhancement phase helps participants recreate personal stories that highlight meaning, agency, and resilience rather than shame. NECT emphasizes that the process of creating and sharing an articulate life narrative is a non-stigmatizing and restorative act to regain a sense of self-efficacy and control (Yanos et al., 2015).

Coming Out Proud (COP) is a brief, three-session, peer-led program that supports participants in exploring personal decisions about disclosure. Using models from the LGBTQ+ community and motivational interviewing techniques, COP helps individuals weigh the pros and cons of sharing their experiences of mental illness, identify safe settings for disclosure, and

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construct empowering self-narratives. Although not designed as therapy, it functions as a consciousness-raising intervention that reduces secrecy, self-stigma, and internalized shame through open dialogue and peer validation (Yanos et al., 2015).

The Anti-Stigma Photovoice intervention (Rusinova et al. 2014, as cited in Yanos et al., 2015) introduces a participatory, creative approach to combating self-stigma. Participants use photography to capture aspects of their daily lives and then create written or spoken narratives that explain the images through guided reflection questions (the “SHOWED” method). This process merges psychoeducation with artistic expression and collective dialogue. It allows participants to challenge stereotypes, celebrate strengths, and create visual testimony of resilience. Photovoice interventions have been shown to increase empowerment, stigma coping, and perceived recovery (Yanos et al., 2015).

The review offered an in-depth comparison and contextual understanding of how these programs performed. Yanos et al. (2015) demonstrated strong credibility by focusing on studies that were mostly randomized or quasi-experimental in design. At the same time, the authors acknowledged that this area of research is in its early stages, with most findings limited to small pilot studies that make generalizing difficult. They emphasized the need for the development of fidelity metrics and standardized toolkits to support widespread implementation.

Yanos and colleagues (2015) concluded that tailored interventions considering individual backgrounds, cultural context, and stigma are most likely to succeed. This finding is consistent with several previously reviewed studies that emphasized the role of culture and stigma in shaping caregiver experiences and the effectiveness of support interventions. For caregivers navigating the emotional stress of raising a child with a disability, these insights offer powerful direction for designing mental health programs that inform and heal.

Summary of Findings for RQ3: Key Characteristics of Social Support Programs

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The studies reviewed in this section highlight the diverse and evolving field of caregiver support programs. Frantz et al. (2017) demonstrated that interventions rooted in emotional wellness, such as mindfulness and cognitive-behavioral approaches, can lead to substantial improvements in caregiver mental health when designed with caregivers' needs at the center. Dykens et al. (2014) reinforced the power of brief, peer-led programs to reduce stress and build resilience, while Lodder et al. (2020) showed that stigma-focused group interventions like SOLACE can significantly improve mental health and self-esteem. Lee et al. (2023) added that peer-to-peer mentorship models are particularly impactful in underserved communities, offering relational and scalable support. Damianakis et al. (2016) extended these insights by showing that online video-based groups can replicate many of the emotional benefits of in-person sessions, helping caregivers reduce isolation, share coping strategies, and feel validated in their roles.

Adding a qualitative perspective, Riley and White (2016) showed emotional safety, peer understanding, and a sense of belonging are central to success. Their findings emphasize that shared identity and emotional validation allow participants to feel seen, valued, and less isolated. These kinds of emotional connections are essential for caregivers, who often feel alone or misunderstood in typical support settings.

Russa et al. (2014) emphasized that organizations must build strong support systems into the larger structures that serve families. They argued that successful programs should include consistent services, strong communication between families and professionals, and respect for cultural differences. Their work highlights the importance of flexibility, family partnership, and follow-through from schools and community agencies. In a different but related focus, Yanos et al. (2015) explored how psychological strategies like helping people change negative thoughts or reshape their personal stories can reduce self-blame and emotional stress.

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Although their review focused on people with mental health conditions, the strategies are also helpful for caregivers of children with ASD.

Together, these studies suggest that caregiver programs work best when they not only teach skills but also strengthen confidence and support identity. The most effective interventions connect families to reliable systems of care, creating emotional and structural foundations.

Summary of Literature Review Findings

Together, the literature clarifies how caregiver stress, perceived support, and program design fit together and where schools and community partners can provide support.

Parents of children with ASD report more stress than other parent groups. Stress rises with daily caregiving demands and barriers like delayed or fragmented services. It eases when families feel they have dependable emotional, informational, and practical support (Hayes & Watson, 2013; Resch et al., 2010). Predictors such as child adaptive functioning and service wait times help explain differences in a families' stress and the need for timely, coordinated, family-centered help (Rivard et al., 2014).

Evidence shows that support works best when it matches families' circumstances and barriers. For example, instrumental supports such as respite care are linked to lower stress when access is reliable and equitable (Christie et al., 2022). Informational supports that are culturally designed (delivered in the families' language and aligned with their values) build confidence and coping (Al-Khalaf et al., 2013; Chiang, 2014).

Home-based videoconferencing groups reach families with distance and mobility barriers and are tied to reduced isolation and improved health knowledge (Banbury et al., 2018). A national qualitative survey documented persistent needs for emotional reassurance, clear and timely information, and peer connection, especially in areas where stigma discourages individuals to seek help (Wakimizu & Fujioka, 2024). Together, these findings emphasize that

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sustainable, school-based support systems must be flexible enough to meet practical needs, reduce barriers, and provide families with consistent emotional and peer connection.

Effective programs share common qualities including being caregiver-centered, culturally responsive, accessible, and peer-affirming. Mindfulness and behaviorally oriented groups improve psychological well-being when caregiver needs are central (Dykens et al., 2014; Frantz et al., 2017). Stigma-reduction programs strengthen identity, connection, and mental health by combining cognitive reframing and guided narrative work in safe, small groups (Lodder et al., 2020). Peer-to-peer models (in person or online) build self-efficacy, reduce isolation, and expand access, outcomes most crucial in underserved communities (Damianakis et al., 2016; Lee et al., 2023). Systems-level guidance stresses family-school collaboration, dependable access, and cultural responsiveness for sustainability. Approaches that address internalized stigma reinforce engagement and caregiver identity (Russa et al., 2014; Yanos et al., 2015).

In summary, perceived support is associated with lower caregiver stress. Specific supports such as respite care, culturally responsive parent education, and peer connection repeatedly improve outcomes. Programs are most effective when they integrate emotional, informational, and instrumental elements, and when delivery is accessible, aware of stigma, and peer supported.

Limitations and Considerations

While the literature offers critical insights, there are several limitations. First, most samples consisted mainly of White, middle-class mothers. This limits the generalizability of findings and highlights the need for further research to engage fathers, grandparents, culturally diverse families, and caregivers in rural or low-income communities. Second, although many interventions demonstrated short-term gains in caregiver well-being, few studies tracked long-term outcomes. This gap creates uncertainty about the sustainability of observed benefits over time. Studies using videoconferencing or online support platforms were limited to small pilot

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groups. They offered no evidence of whether the benefits continued once the programs ended. These findings suggest the potential of digital models but also highlight the need for larger samples and longer follow-up. Additionally, while many articles stated the importance of reducing stigma, few explained clear, research-based strategies to achieve this goal across diverse communities.

Third, participants often mentioned emotional support and a sense of belonging as valuable but did not always measure them directly. Future research should examine how belonging and emotional connection shape caregiver outcomes. Finally, service access remains a significant challenge. Families most in need of support, especially those with multiple diagnoses or systemic disadvantages, often face the greatest barriers. Policymakers, financial stakeholders, and community leaders should address these network inequities.

Implications for Practice, Policy, and Research

Future research and implementation efforts should focus on the following priorities:

- Expanding caregiver inclusion in study samples, especially underrepresented populations.
- Designing and testing long-term, scalable interventions that measure caregiver outcomes over time.
- Integrating digital and hybrid delivery models to help families in remote or mobility-limited areas.
- Embedding caregiver voice through design processes that shape support programs from beginning to end.
- Attending to emotional safety, belonging, and shared identity as essential parts of caregiver support.

Overall, the availability and quality of support systems profoundly shape caregiver stress. Programs that are culturally informed, peer-driven, and family-centered show the most

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promise in reducing stress and strengthening caregiver resilience. Online platforms have also demonstrated potential to extend access to these programs, but they must be carefully structured and sustained to maintain effectiveness. Strong caregiver support is a necessity for the well-being of families raising children with autism and other disabilities. These findings serve as the foundation for the Parent Support and Resilience Plan for Families of Children with ASD (PSRP) presented in Section 3.

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SECTION 3: A PLAN TO MITIGATE THE PROBLEM

Parents of children with ASD consistently experience high stress, limited support, and ongoing stigma, challenges that can erode their well-being over time (Hayes & Watson, 2013; Papadopoulos et al., 2018; Resch et al., 2010). While many find creative ways to cope, the literature shows that schools and communities rarely provide coordinated systems of support (Meadan et al., 2010). Caregivers are often left to navigate a maze of services on their own, which not only elevates their stress but also weakens the long-term resilience of families (Rivard et al., 2014).

The plan is shaped by Ecological Systems Theory and Family Systems Theory. Ecological Systems Theory, when applied to families, suggests that families are influenced by many layers of their environment, from home and school to district policies, and cultural views (Bronfenbrenner, 1979, 1985). When applying the Ecological Systems Theory for this work, it highlights why the plan must involve not only teachers and parents but also school administrators and community leaders. For example, flexible IEP meeting times or district-provided caregiver resource liaisons are initiatives at the level of the exosystem that have the potential to reduce stress for families. Family Systems Theory highlights that stress experienced by one member had the potential to affect the entire family unit (Bowen, 1978; Minuchin, 1974). For example, when a caregiver feels burned out, the marriage relationship may suffer, siblings may feel ignored, and the child's progress may be affected. By applying Bowen's framework, this plan emphasizes strategies that support caregivers directly (e.g., peer groups and respite referrals) while also strengthening the family relationship. Placing these theories at the center ensures that the plan supports the family as a whole along with the larger systems that influence family well-being.

Definition of Family

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For this capstone, the term *family* refers to the primary caregivers responsible for the day-to-day care, decision-making, and emotional support of a child with ASD. This includes biological or adoptive parents, legal guardians, or another adult who assumes a primary caregiving role. These individuals are most likely to attend caregiver support groups, complete stress-screening tools such as the PSS-10, and receive referrals for respite or other supportive services.

While extended family members or community members may contribute meaningful assistance, they are not considered primary recipients of the supports described in this paper unless they serve as the child's primary caregiver. This definition recognizes that primary caregivers experience the greatest caregiving demands. It also aligns with Family Systems Theory, which positions them as central to family functioning and support needs.

This plan outlines a path for meaningful support. It drew directly from the findings in Section Two and converts them into four core recommendations designed to address families' immediate realities and to build capacity over time. Each recommendation is grounded in research and reflects the realities parents describe. Specifically, families report the need for immediate relief (Christi et al., 2022; Resch et al., 2010), the desire for trustworthy information (Chiang, 2014; Meadan et al., 2010), the importance of peer connection (Damianakis et al., 2016; Riley & White, 2016), and the power of reducing stigma (Gray, 2002; Lodder et al., 2020; Papadopoulos et al., 2018).

These recommendations are followed by practical, actionable steps that schools and community partners can implement to improve caregiver well-being. At the same time, they provide a framework for long-term change. By investing in support that relieves stress, expands knowledge, fosters peer connections, and promotes caregiver pride, school districts can create conditions where parents feel less isolated and more equipped to care for their children.

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The sections that follow describe each recommendation in detail, along with the rationale for its inclusion, examples of how it might be implemented, and connections to the broader goals of reducing caregiver stress and strengthening family resilience. The recommendations are followed by a description of my proposed plan, the Parent Support and Resilience Plan (PSRP). The PSRP is a multi-strategy initiative designed to improve caregiver well-being in the Eagles Nest School District (a pseudonym used for confidentiality). Although not every component will be put into action immediately, the plan offers a blueprint grounded in research and caregiver voice. The accompanying product, The Parent Support and Resilience Plan Field Guide (PSRP-FG), focuses on the strategies that school personnel can realistically implement now, such as peer support and caregiver education. Other elements of the plan highlight future opportunities for development.

Four Core Recommendations (Caregiver Needs)

This plan builds on the common patterns researchers identified across their studies. Although the studies explored different aspects of caregiving, many pointed to the same core needs. These needs shaped the four recommendations outlined in this section and the four strategies that follow. Together, they highlight that parents of children with ASD require more than isolated services. They need coordinated, evidence-based supports that address stress, provide education, promote peer connection, and reduce stigma (Lodder et al., 2020; Papadopoulos et al., 2018). These coordinated supports include emotional and informational resources as well as instrumental supports such as respite services and access to mental health care, which provides immediate and practical relief.

Recommendation 1: Provide Immediate Relief Through Practical Supports

This plan is grounded in key findings from the literature and shaped by four evidence-based recommendations. Hayes and Watson (2013), Meadan et al. (2010), and Rivard et al. (2014) demonstrated that stress in caregiving is emotional and structural. Long service delays,

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limited respite care, and inaccessible systems create long-term strain. Recommendation One responds directly to these challenges.

Parents of children with ASD often face overwhelming daily demands that leave little time for rest or recovery. Without timely support, caregivers can become exhausted and experience burnout, which not only harms their own well-being but also impacts family functioning and child outcomes (Dykens et al., 2014; Hayes & Watson, 2013; Waqar et al., 2024). Rivard (2014) found that long wait times for services significantly increase parental stress, showing how systemic delays intensify family strain. Christi (2022) demonstrated that respite care reduced stress, anxiety, and depression for military families raising children with ASD, a finding especially relevant to districts serving military-connected communities.

Research consistently shows that respite services and accessible mental health supports reduce caregiver stress and help parents sustain their caregiving role (Resch et al., 2010; Wakimizu & Fujioka, 2024). These services provide immediate relief that enables parents to manage daily caregiving demands more effectively. Schools and districts can help by connecting families to respite programs, offering flexible scheduling for school-based services, and partnering with community organizations to improve mental health access. When caregivers have consistent access to these supports, they are better positioned to participate in longer-term strategies such as education, peer networks, and advocacy (Lodder et al., 2020; Meadan et al., 2010).

Recommendation 2: Expand Caregiver Knowledge Through Education and Empowerment

Other studies, such as those by Chiang (2014) and Al-Khalaf et al. (2013), showed that structured, culturally responsive education programs significantly improved caregiver coping and mental health outcomes. Wakimizu and Fujioka (2024) further demonstrated that parents consistently rank trustworthy information and guidance as top support needs. These findings

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directly guide Recommendation Two, which emphasizes the power of culturally specific training and practical information.

Knowledge is a powerful form of support. Parents frequently report confusion when navigating the special education system, identifying community resources, or understanding their child's developmental needs. Research indicates that when caregivers receive targeted education and training, they gain confidence, report lower stress levels, and feel better equipped to support their families (Meadan et al., 2010; Resch et al., 2010).

Culturally responsive programs strengthen these outcomes. Chiang (2014) found that Chinese-American parents who attended education sessions reported improved coping strategies and advocacy skills. Al-Khalaf (2013) showed similar results among mothers in Jordan, demonstrating that when information is delivered in ways that honor culture, language, and community values, parents report higher confidence and reduced stress. Wakimizu and Fujioka (2024) reinforced this finding by showing that caregivers consistently value clear and trustworthy information as a primary form of support.

A systematic review by Frantz et al. (2017) confirmed that psychoeducation, cognitive-behavioral strategies, and mindfulness programs consistently improve caregiver well-being by reducing stress, anxiety, and depression while enhancing self-efficacy. Their findings strengthen the case for making education and empowerment central to caregiver support. When schools offer structured workshops, practical resources, and culturally relevant materials, they provide information and give families the tools they need to thrive.

Recommendation 3: Build Peer-Led Resilience Through Connection

Peer connections emerged as another consistent theme. Lodder et al. (2020), Papadopoulos et al. (2018), and Lee et al. (2023) demonstrated that parent-to-parent programs reduce isolation and promote resilience by creating environments for support and advocacy. Banbury et al. (2018) and Damianakis et al. (2016) highlighted how both in-person and online

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peer networks provide sustainable help for families. These findings anchor Recommendation Three which emphasizes mentorship and group support as vital to long-term caregiver well-being.

Caregivers often find their most meaningful support in one another. Peer connections validate shared experiences, reduce isolation, and provide models of resilience. Studies demonstrate that parent-led groups, mentorship, and online communities contribute to lower stress and encourage a strong sense of belonging (Lodder et al., 2020; Papadopoulos et al., 2018).

Banbury et al. (2018) and Damianakis et al. (2016) demonstrated that modest peer initiatives, such as mentorship partnering or online groups, can significantly improve caregiver coping and reduce feelings of isolation. Frantz et al. (2017) confirmed the effectiveness of peer supports as part of integrated interventions that combine psychoeducation, coping strategies, and community connection. These findings show that caregiver resilience improves when families develop networks founded on lived experiences.

By creating school-based peer groups or parent mentor programs, districts can make these supports accessible and sustainable. These kinds of efforts meet immediate emotional needs and foster resilience, advocacy, and long-term community participation.

Recommendation 4: Reduce Stigma and Promote Caregiver Pride

Stigma repeatedly surfaced as a barrier to caregiver health. Gray (2002) and Papadopoulos et al. (2018) documented its harmful effects, while Yanos et al. (2015) and Lodder et al. (2020) showed that structured interventions and public recognition can reduce stigma and foster pride. Peer-to-peer models present an effective strategy for reducing isolation and building caregiver pride. Lee et al. (2023) confirmed that peer groups strengthen advocacy while reframing caregiving as a source of pride rather than shame. Together, these insights

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shape Recommendation Four, which calls for programming that affirms caregivers' strengths and counters negative stereotypes.

Evidence-Based Anti-Stigma Approaches

Drawing on evidence from the mental health field, Yanos et al. (2015) identified several structured interventions that effectively reduce self-stigma by helping participants explore, reframe, and share their experiences. These practices demonstrate how caregivers can use reflection, narrative, and peer connection to transform feelings of shame into empowerment:

- **Narrative Enhancement and Cognitive Therapy (NECT)**

A group-based intervention that combines cognitive restructuring with narrative-building exercises. Participants identify the challenge negative self-beliefs, develop alternative personal stories, and strengthen self-esteem through guided group reflection.

- **Ending Self-Stigma (ESS)**

A structured psychoeducational program that helps individuals recognize, manage, and challenge internalized stigma. The approach integrates cognitive-behavioral strategies with peer discussion to promote self-acceptance and resilience.

- **Coming Out Proud (COP)**

A brief, peer-led intervention that focuses on disclosure and empowerment. It helps participants decide whether, when, and how to share personal experiences, emphasizing values-based decision-making and pride in one's caregiving identity.

Stigma remains one of the most damaging challenges for parents of children with ASD (Gray, 2002; Papadopoulos et al., 2018). Many describe feeling judged, excluded, or misunderstood, which worsens stress and discourages help-seeking. Research shows that stigma can be both external, through negative public attitudes, and internal, when caregivers begin to doubt their worth (Corrigan & Watson, 2002; Kinnear et al., 2016).

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Peer-to-peer (P2P) models present an effective strategy for reducing isolation and building caregiver pride. Lee (2023) found that peer support reduced feelings of stigma while increasing caregiver pride and confidence. Parents valued hearing from others who had walked the same path, which reduced feelings of stigma and instilled pride in their caregiving identity. Structured stigma-reduction interventions from the mental health field also provide useful models. Yanos et al. (2015) identified evidence-based approaches, such as Narrative Enhancement and Cognitive Therapy, Ending Self-Stigma, and Coming Out Proud, that successfully reduced self-stigma, improved self-esteem, and increased hope. Although developed for different populations, these interventions show how purposeful programming can help parents of children with ASD replace shame with pride.

Lodder et al. (2020) added that stigma-reduction efforts gain strength when combined with increased awareness efforts and school-based recognition of caregiver strengths. By integrating both structured interventions and community recognition into caregiver programs, schools can create supportive environments where parents feel valued and empowered.

Designing a Multi-Strategy Support System for Caregivers of Children with ASD

The overall plan builds on four connected strategies that derive directly from the four recommendations described above: Immediate Relief, Education and Empowerment, Peer Leadership, and Reducing Stigma (Hayes & Watson, 2013; Papadopoulos et al., 2018; Resch et al., 2010). These strategies reflect caregiver-identified needs and align with efforts to reduce stress and strengthen family well-being (Meadan et al., 2010; Wakimizu & Fujioka, 2024). The PSRP begins with immediate relief. It concludes with long-term peer-driven support, reinforced by efforts to fight stigma and promote caregiver pride (Gray, 2002; Lodder et al., 2020) (see Figure 3). These categories function as complementary approaches rather than sequential stages. While research supports all four, the accompanying product emphasizes the strategies

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most feasible for school personnel to implement. The others offer recommendations for future development.

The plan integrates caregiver perspectives, evidence-based practices, and system-level factors to ensure it is sustainable, scalable, and school-level adaptable. Each strategy matches themes emerging from the literature and organizes its work around specific goals, benchmarks, and implementation practices. Together, these strategies form a well-connected framework to support caregivers in meaningful and lasting ways within the school and community environment.

Insights Informing the Plan

Studies by Wakimizu and Fujioka (2024) and Waqar et al. (2024) stress the importance of trust, inclusion, and access in reducing caregiver stress. While Waqar and colleagues focused on families facing economic and educational hardship, Wakimizu and Fujioka found that even when help is available, caregivers may avoid it if the setting feels cold, rushed, or judgmental. Together, these findings reinforce the idea that support must be available, emotionally secure, and culturally respectful to be effective (Papadopoulos et al., 2018).

From Recommendations to Strategies: Linking Needs With Actions

The four recommendations form the foundation of the Parent Support and Resilience Plan (PSRP). Not every component of the plan will be implemented immediately, but together they represent a practical and scalable framework grounded in caregiver voices and supported by research. The PSRP provides schools and districts with actionable paths to reduce stress, strengthen perceived support, and build long-term resilience among families of children with autism.

As part of this project, a practical product has been developed, the Parent Support and Resilience Plan Field Guide (PSRP-FG). This guide is designed for district leaders, school staff, and community partners. It organizes the four recommendations into clear strategies, steps,

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tools, and resources that can be used in everyday practice. The Field Guide serves as the hands-on part of the plan, turning research into simple, usable actions for schools and families. A full description of the Field Guide and its implementation is provided in Section 5.

Frantz et al. (2017) reinforced the need for an integrated approach. Their review of 41 interventions confirmed that caregiver well-being improves most when strategies combine psychoeducation, coping skills, mindfulness, and peer support. This evidence validates the design of the PSRP, which combines relief, education, peer leadership, and stigma reduction into an organized framework.

The PSRP also builds on the principle that caregivers are experts in their own experiences. Their stories, insights, and strengths can help other families feel less overwhelmed. By offering trained mentorship, regular peer group meetings, and school-facilitated coordination, the plan creates opportunities for caregivers to connect in ways that are meaningful and lasting. While other strategies in the plan focus on professional services and education, this peer-led model ties everything together. It responds to what caregivers have said they need most: someone who understands, someone who listens, and someone who shows them they are not alone. For this reason, Lodder et al.'s (2020) study is essential to the design of this project.

The four recommendations helped shape each aspect of the PSRP. Their order aligns with the strategy's approach, beginning with real-life caregiving challenges, progressing to education and empowerment, culminating in peer-led support that fosters connection and combats stigma. Caregivers do not simply need information or services; they require support that addresses multiple aspects of their experience and their family needs. Each foundational strategy in this plan directly responds to these four recommendations, turning research into clear, school-based, and actionable steps.

Anchoring the Plan in a Central Study

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Although many studies have influenced this plan, the research from Lodder et al. (2020) helped shape its overall design. Their work stands out because it focused on reducing caregiver stress through peer leadership and achieved it in a way that was structured, practical, and grounded in the real lives of families raising children with autism. Instead of offering general recommendations, the authors described a specific, low-cost program called *SOLACE*, which trained parents to support each other in small groups over time.

The results were clear; the group approach was effective. Parents who joined peer-led groups reported feeling less isolated, more confident, and better able to cope with daily challenges. Many also said the emotional support they received from other parents was just as important as any professional help they had experienced. The study showed that caregivers found validation and respect when talking with people who had been through similar challenges. These findings confirm what other researchers have reported, but Lodder et al. (2020) demonstrated exactly how schools and communities could turn those ideas into action.

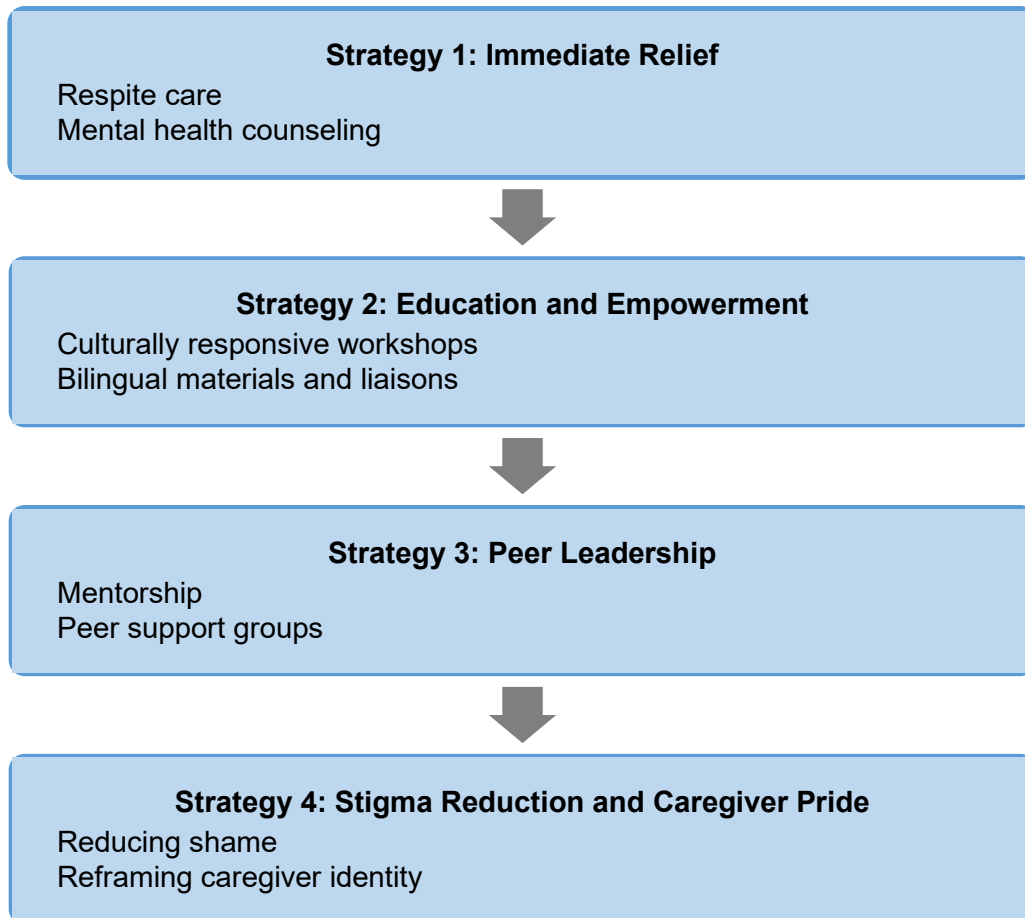
Foundational Strategies (Implementation Plan)

Figure 2 illustrates the four strategies of the PSRP and how they interconnect. Each strategy is summarized below, followed by a detailed description of its implementation.

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Figure 2

Implementation Plan



This figure presents four strategic categories of caregiver support identified in the literature.

Strategy 1 (Immediate Relief) includes services such as respite care and mental health counseling to address urgent needs. Strategy 2 (Education and Empowerment) provides culturally responsive workshops and bilingual supports to equip caregivers with knowledge and practical tools for reducing stress, navigating service systems, advocating for their children’s needs, and fostering positive family routines. Strategy 3 (Peer Leadership) promotes long-term well-being through mentorship and small peer support groups. Strategy 4 (Stigma Reduction and Caregiver Pride) addresses the harmful effects of stigma by fostering pride, reducing shame, and reframing caregiver identity in positive, strength-based ways.

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Strategy One: Deliver Immediate Relief Through Respite and Mental Health Supports

The first part of the 12-month plan begins with a clear, research-based rationale that caregivers benefit from timely, hands-on, and accessible support. Christi et al. (2022) found that respite and mental health services lowered stress and helped families feel more stable. Meadan et al. (2010) also showed that stress builds up over time due to delays or services that are hard to navigate. Starting early helps families recover from stress and stay connected to the systems meant to support them.

This strategy emphasizes reducing caregiver stress by improving access to short-term respite care and mental health services. Respite care represents a tangible example of instrumental support, giving parents time away from their responsibilities so they can restore energy and maintain long-term caregiving capacity. Research indicates these supports are among the most effective ways to offer quick relief to families experiencing stress (Christi et al., 2022; Meadan et al., 2010; Waqar et al., 2024). Many caregivers face long waitlists, limited resources, and complex daily demands. By offering targeted help early on, this strategy helps families stabilize and cope more effectively.

Implementation begins at the school level. School-based teams, such as special education staff, school counselors, and family liaisons, should identify caregivers experiencing high stress using a screening tool, such as the Perceived Stress Scale (PSS-10), teacher referrals, case managers, or caregiver self-referral (Meadan et al., 2010; Resch et al., 2010). Once identified, schools can use formal partnerships and a coordinated referral process to connect families with local respite providers, autism-literate counselors, and the Exceptional Family Member Program (EFMP) (Christi et al., 2022; Rivard et al., 2014).

At the district level, the special education director and student services coordinator should oversee implementation over a six-month rollout. During the first two months, leaders can identify service partners, formalize agreements, and design the referral system (Hayes &

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Watson, 2013). In the third month, school administrators and designated support staff should be trained to assist caregivers (Lodder et al., 2020). From months four through six, school-based teams can begin actively referring families and tracking participation and outcomes (Waqar et al., 2024).

Progress should be measured by tracking the number of caregivers who receive support, changes in their stress levels over time using the PSS-10, and caregiver satisfaction with services (Christi et al., 2022; Lodder et al., 2020). Potential challenges include a shortage of local providers, stigma around seeking help, and delays in communication between teams. District leadership should prepare by maintaining a list of backup providers in nearby areas, sharing resources that normalize requests for help, and designating a point of contact to manage the communication between schools and service providers (Rivard et al., 2014; Waqar et al., 2024).

Building on their earlier findings, Dunst et al. (1988) showed that when families have access to adequate resources, their overall well-being and participation in early intervention improve. This evidence reinforces that immediate relief strategies are not just short-term fixes but also critical to protecting long-term family functioning.

This first strategy gives families a chance to regain stability and agency. With reduced stress, caregivers are better prepared to participate in the educational and peer support activities outlined in the following strategies (Hayes & Watson, 2013; Meadan et al., 2010).

Strategy Two: Expand Knowledge Through Education and Empowerment

Caregivers often report uncertainty when navigating service systems or advocating for their children. Research shows that targeted education reduces stress and increases confidence, giving families practical tools to manage daily challenges (Meadan et al., 2010; Resch et al., 2010). Chiang (2014) found that culturally designed parent education programs that consider language, traditions, or past negative experiences improved coping and advocacy

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among Chinese-American families. Al-Khalaf et al. (2013) demonstrated similar benefits for Jordanian mothers. These studies show that when programs are aligned with caregivers' cultural contexts, they strengthen engagement and lower stress.

This strategy centers on providing caregivers with relevant, accessible information through workshops that address the practical and emotional aspects of raising a child with ASD. The core content should include stress management, communication with schools, strategies for positive family routines, and information about services. Workshops must be delivered in culturally and linguistically responsive ways, with bilingual staff, translated materials, and sensitivity to diverse family backgrounds (Wakimizu & Fujioka, 2024).

In culturally diverse communities, a cultural liaison is typically a community-based, not school-employed individual who has earned trust within the cultural group. This person may be a community organizer, advocate, or faith-based leader. Within the PSRP, the cultural liaison would collaborate with school personnel to co-lead workshops and outreach activities, reducing cultural and language barriers and increasing family engagement.

Implementation of this educational strategy requires intentional collaboration between schools, community organizations, and family leaders. School districts can host recurring workshops facilitated by special educators, social workers, and trained parent mentors. Each workshop should combine evidence-based content with time for discussion, so parents leave with knowledge and a sense of community. Recommended topics would include understanding the Individualized Education Program (IEP) process, learning about available services, supporting emotional well-being at home, and handling common challenges in raising a child with ASD (Gallagher et al., 1983; Meadan et al., 2010). Sessions may be offered in person or virtually to improve accessibility (Banbury et al., 2018; Waqar et al., 2024).

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Dunst and Trivette (2009) emphasized that caregiver education is most effective when it follows a capacity-building model, equipping parents with skills they can use independently of trained professionals. This approach ensures that training builds agency and resilience.

Evaluation should include measures such as attendance, caregiver self-reports of confidence and knowledge, and changes in perceived stress. Stress screenings (PSS-10) will capture immediate relief needs, while the WHOQOL-BREF will track longer-term improvements in overall caregiver quality of life. Frantz et al. (2017) confirmed that interventions integrating psychoeducation, coping skills, and mindfulness yielded measurable improvements in caregiver mental health. Using these outcomes as benchmarks will help districts assess progress and ensure the PSRP is evaluated for its short-term responsiveness and capacity to sustain family resilience.

The specific rollout of this strategy may vary across school systems, but the comprehensive tasks and responsibilities are described in the section Implementation Timeline and Roles. The implementation timeline ensures that caregiver education is research-based and realistic within the district.

By empowering caregivers with knowledge and practical tools, this strategy strengthens resilience and ensures families are equipped to advocate effectively. Education builds confidence, reduces uncertainty, and prepares parents to engage more fully with other supports in the plan.

Strategy Three: Build Peer Leadership Through Mentor Programs and Support Groups

This strategy emphasizes creating networks of peer mentors and small support groups that allow caregivers to share strategies, celebrate progress, and cope with stress together. Studies of online and hybrid groups (Banbury et al., 2018; Damianakis et al., 2016) confirm that even modest, low-cost initiatives can provide lasting benefits when facilitated effectively.

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Implementation involves training experienced caregivers to serve as mentors and establishing regular group meetings hosted at schools, community centers, or through virtual platforms. Schools can collaborate with community organizations to ensure that groups are culturally inclusive, accessible, and welcoming. Peer leaders can provide guidance to new caregivers, particularly during the stressful period following diagnosis, by sharing perspectives grounded in lived experience.

Dunst (1986) argued that family support must extend beyond the parent-child dyad to include wide networks of assistance. Peer-led programs reflect this systems perspective by recognizing that caregiver well-being improves when families connect with others who share their experiences.

Success can be measured through participant feedback, reductions in reported stress and isolation, and increased caregiver involvement in school and community activities. Frantz et al. (2017) confirmed that interventions were most effective when peer support was included alongside education and coping strategies, emphasizing the value of this approach.

Peer-led resilience strategies help caregivers see themselves as more than just service recipients, but also as contributors to a larger community. By strengthening networks of mutual support, this strategy reduces isolation and builds a foundation of lasting resilience.

Strategy Four: Reduce Stigma and Promote Caregiver Pride

Despite increasing awareness of autism, stigma continues to weigh heavily on families. Caregivers often report feeling judged, misunderstood, or excluded because of their child's diagnosis (Gray, 2002; Papadopoulos et al., 2018). This stigma isolates families and undermines caregiver well-being and access to support. Yanos et al. (2015) showed that self-stigma interventions for mental health populations can reduce internalized shame and increase empowerment, findings that are especially meaningful to caregivers of children with ASD.

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This strategy focuses on initiatives that challenge stigma and promote caregiver pride. Programs can highlight caregiver voices through storytelling, community events, and school-based efforts that normalize the realities of raising children with ASD. Interventions such as narrative enhancement, photovoice, and peer-led discussions (Frantz et al., 2017; Lodder et al., 2020) demonstrate that when caregivers share their experiences publicly, they feel more confident and supported while communities develop increased understanding.

Implementation can begin with small-scale awareness events and parent committees facilitated by schools. These activities should amplify caregiver perspectives, highlight cultural diversity, and offer positive images of families raising children with ASD. Over time, schools can embed stigma-reduction practices into school-wide programming, such as professional development for staff, family workshops, and partnerships with local organizations.

Success can be measured by tracking caregiver self-reports of stigma and pride, community participation in awareness activities, and qualitative feedback from families. Papadopoulos et al. (2018) emphasized that reducing stigma not only improves mental health outcomes but also strengthens family resilience, making this a critical element of any long-term plan.

By directly addressing stigma and promoting caregiver pride, this strategy reshapes how families are perceived by themselves and by their communities. It ensures that support efforts are practical and affirming, creating an environment where caregivers feel respected, valued, and empowered.

Implementation Timeline and Roles

The implementation of the Parent Support and Resilience Plan Field Guide (PSRP-FG) follows a 12-month implementation timeline to support the rollout of its four foundational strategies across schools and the district. The timeline outlines key activities for each strategy and identifies responsibilities for district- and school-level staff to maintain focus and alignment

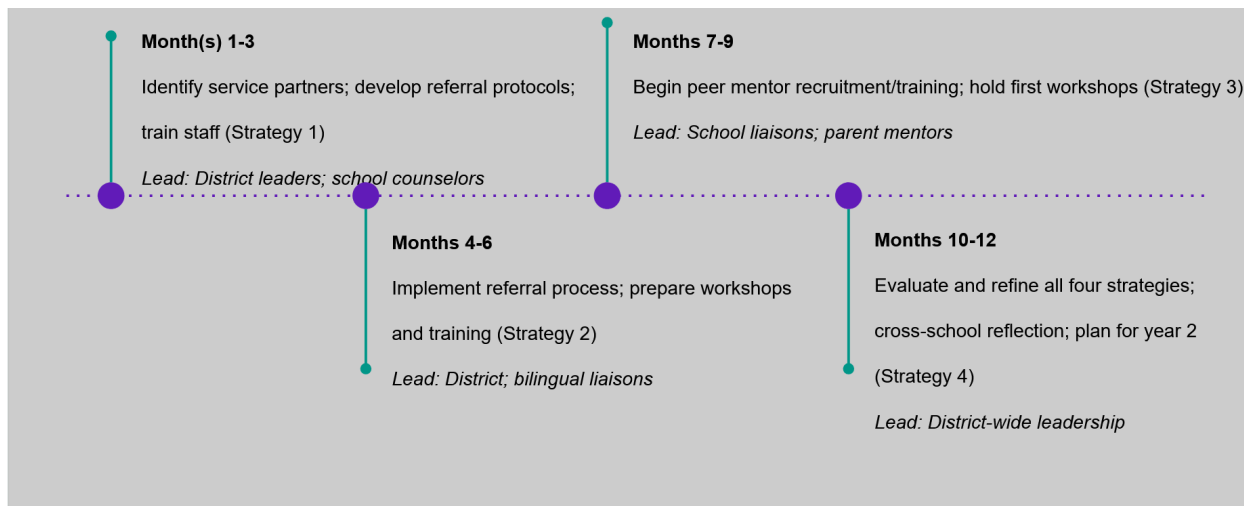
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across sites. Consistent communication and clearly defined roles are necessary to provide caregivers with timely and coordinated support (Hayes & Watson, 2013; Waqar et al., 2024).

Figure 3 provides a visual summary of this phased implementation plan.

Figure 3

12-Month Implementation Timeline for the Parent Support and Resilience Plan



Note: This figure outlines the rollout schedule and role responsibilities across a 12-month period, aligning the four strategies with key planning benchmarks.

During months one through three, district leaders can prioritize launching Strategy One by identifying respite and mental health service partners, developing referral protocols, and training school staff in caregiver intake and support procedures (Christi et al., 2022; Lodder et al., 2020). At the same time, schools should begin identifying caregivers who may need additional support, including creating clear opportunities for self-referral. For those who choose to participate, tools such as the PSS-10 can provide insight into stress levels of stress (Meadan et al., 2010; Resch et al., 2010). The WHOQOL-BREF can offer a picture of overall quality of life across physical, psychological, social, and environmental domains (WHOQOL GROUP, 1998). Both tools can guide initial planning and provide a reference point for evaluating progress over time.

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From months four through six, staff can implement the referral process, and participating caregivers can begin accessing services. During this stage, schools should also collaborate to create and review culturally responsive workshop materials, while designated staff receive training to facilitate caregiver education (Papadopoulos et al., 2018; Rivard et al., 2014).

By months seven through nine, leaders can introduce Strategy Three. Schools can begin recruiting and training caregiver mentors, creating support group schedules, and piloting the first peer-led sessions (Lee et al., 2023; Lodder et al., 2020; Wakimizu & Fujioka, 2024). By this stage, educational workshops from Strategy Two should be in progress, improved through early caregiver feedback to ensure cultural fit and relevance (Christi et al., 2022; Waqar et al., 2023).

The final quarter, months ten through twelve, can focus on refining all four strategies. Schools should gather data, review outcomes, and make necessary adjustments. Simultaneously, district leaders will help facilitate cross-site reflection meetings, celebrate successes, and plan for year two (Waqar et al., 2023). Although the full plan covers a calendar year, the accompanying practitioner product emphasizes practical resources aligned with Strategy Three that schools can begin using right away.

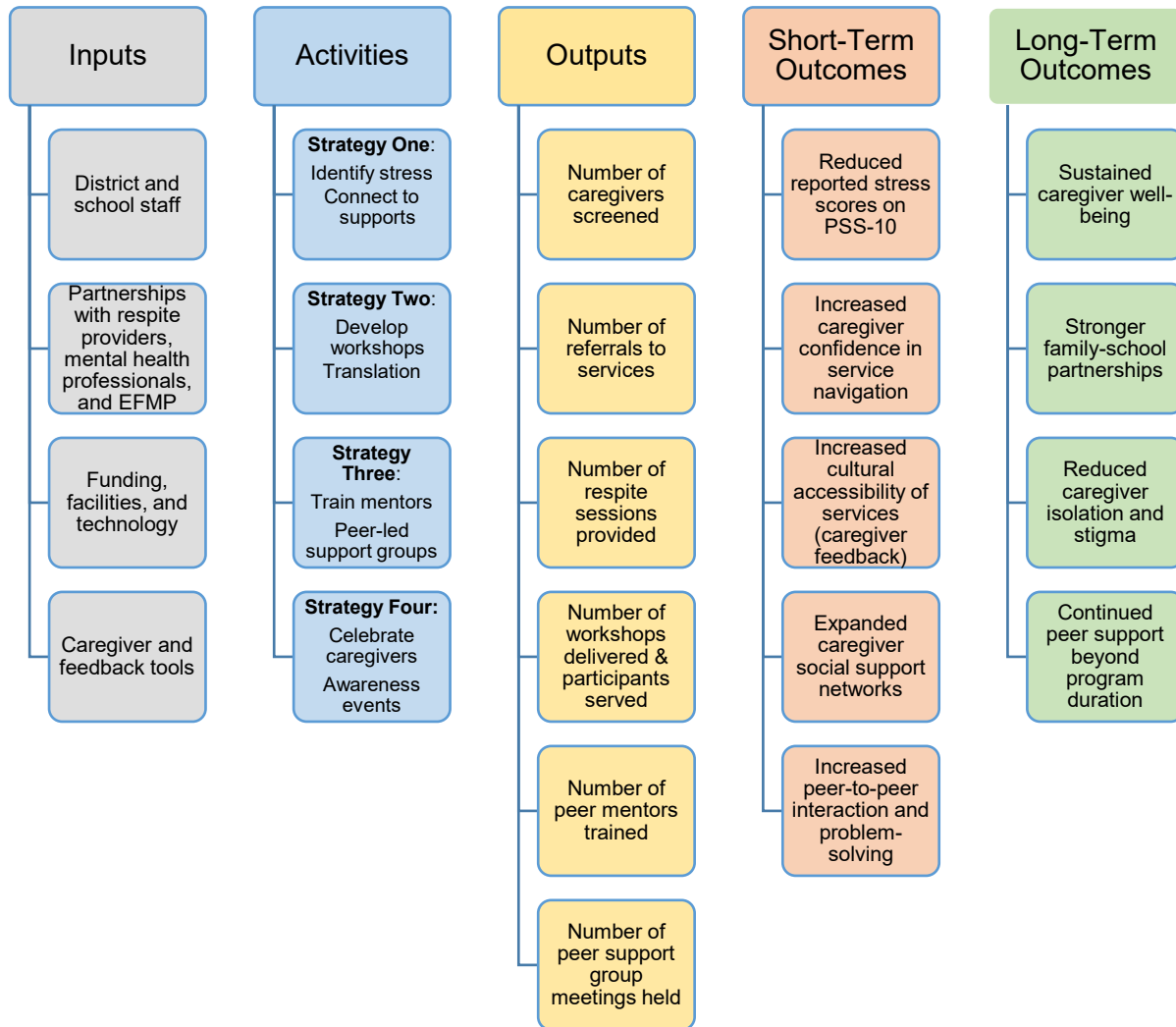
At the district level, leaders such as the Director of Special Education can oversee overall implementation by managing provider contracts, coordinating data collection, and ensuring alignment with district goals (Hayes & Watson, 2013). School principals play a critical role in ensuring consistent implementation by assigning staff to coordinate services and making sure families can easily access support (Resch et al., 2010). Collaboration across all levels is essential to maintaining caregiver trust and sustaining momentum throughout the year (Lodder et al., 2020; Meadan et al., 2010). Figure 4 summarizes the inputs, activities, and intended outcomes of the initiative in a logic model form.

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Figure 4

Logic Model for Parent Support and Resilience Plan



Note This logic model reflects the structure and intended outcomes of the Parent Support and Resilience Plan caregiver support initiative and integrates evidence-based strategies from the literature (Christi et al., 2022; Lodder et al., 2020; Meadan et al., 2010; Papadopoulos et al., 2018; Rivard et al., 2014; Wakimizu & Fujioka, 2024; and Waqar et al., 2023).

Figure 4 shows how the plan’s resources, activities, and outcomes fit together in one framework. It connects immediate supports with long-term goals, making clear how each strategy can lower caregiver stress and build resilience. Hayes and Watson (2013) explained

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that coordinated supports are most effective when they address both short-term needs and long-term well-being. The model also reflects Frantz et al.'s (2017) finding that multi-component plans work best when they are organized. This visual summary highlights the need for accountability, since each activity only works if schools carry it out and track progress. To make sure these strategies lead to real improvements, the next step is a clear system for monitoring and evaluation.

Monitoring and Evaluation Plan

The plan uses precise monitoring and evaluation to track participation, effectiveness, and caregiver experience throughout the 12-month implementation period. The goal is to measure progress for each strategy while ensuring the initiative continues to meet caregiver needs.

Progress should be monitored using clear indicators for each strategy. For Strategy One, data can include the number of caregivers referred to respite and mental health services, pre- and post-stress levels using the PSS-10, and caregiver satisfaction with services (Meadan et al., 2010; Resch et al., 2010). For Strategy Two, evaluation should track workshop attendance, changes in caregiver confidence, and feedback about cultural relevance and accessibility (Papadopoulos et al., 2018; Rivard et al., 2014). For Strategy Three, measures should include mentor and mentee participation, caregiver reports of social support, and reduction in perceived isolation over time (Lee et al., 2023; Lodder et al., 2020). For Strategy Four, evaluation should focus on changes in caregiver empowerment and stigma reduction. Data can include caregiver self-reports of pride and identity, participation in storytelling or community recognition events, and shifts in perceived stigma using surveys adapted from validated measures (Lodder et al., 2020; Yanos et al., 2015). Schools can also document the number and type of stigma-reduction activities implemented (e.g., narrative-sharing events or professional development workshops).

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To make the connection between each strategy and its evaluation measures clearer, Table 2 summarizes the intended outcomes, ways of measuring them, and supporting references.

Table 2

Evaluation Measures for the Four Strategies of the PSRP

Strategy	Intended Outcomes	Evaluation Measures	References
Strategy 1: Immediate Relief	Reduced caregiver stress, improved stability	Pre/post caregiver stress using PSS-10; caregiver satisfaction surveys; service utilization records	Christi et al. (2022); Meadan et al. (2010); Resch et al. (2010)
Strategy 2: Education & Empowerment	Increased caregiver confidence, knowledge, and advocacy skills	Attendance at workshops; pre/post knowledge/confidence surveys; WHOQOL-BREF for quality of life	Al-Khalaf et al. (2013); Chiang (2014); Frantz et al. (2017)
Strategy 3: Peer Leadership	Reduced isolation, increased social support and resilience	Mentor/mentee participation logs; caregiver social support surveys; qualitative feedback from peer groups	Banbury et al. (2018); Damianakis et al. (2016); Lodder et al. (2020)
Strategy 4: Stigma Reduction & Caregiver Pride	Reduced stigma, increased pride and empowerment	Caregiver self-reports of stigma/pride; participation in recognition/storytelling events; stigma survey instruments	Gray (2002); Papadopoulos et al. (2018); Yanos et al. (2015)

Assessments of caregiver stress and well-being will draw on validated instruments, specifically the Perceived Stress Scale (PSS-10) and the World Health Organization Quality of

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Life-Brief Version (WHOQOL-BREF) (Chiang, 2014; Christi et al., 2022). Both instruments have been widely used in caregiver research and demonstrate strong reliability and validity. A detailed description of these measures, including sample items, scoring procedures, and psychometric properties, is provided in Appendix A.

School staff should collect and review data monthly using district-provided tracking forms. At the mid-point and end of the year, district staff should analyze results across all schools to evaluate the program's overall impact and identify areas for improvement. Leaders can then use the findings to adjust delivery, reallocate resources, and refine training efforts (Hayes & Watson, 2013; Waqar et al., 2024).

Evaluation should focus on outcomes and caregiver voice. Ongoing feedback from caregivers, gathered through surveys, brief interviews, and group discussions, should be treated as essential evidence to guide program design and adjustments (Wakimizu & Fujioka, 2024). Focusing on measurable results and caregiver experience helps ensure the initiative remains inclusive, responsive, and aligned with the values of the Eagles Nest School District (Dunst & Trivette, 2009; Gallagher et al., 1983).

Partnership with Families: Process and Participation

Partnership, not just service delivery, forms the foundation of strong caregiver programs. Families should feel they are being listened to, respected, and invited to participate in shaping the support they receive (Chiang, 2014; Gallagher et al., 1983). From the earliest stages, schools should collaborate with families to identify their priorities and ensure services reflect their needs and values (Dunst & Trivette, 2009).

When a caregiver is identified, either through a program referral or by self-referral, an initial intake conversation should be held to understand stress level, language needs, and top concerns. This step also gives families a chance to ask questions and share their goals for participating in the program (Meadan et al., 2010; Resch et al., 2010). A trained staff member,

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such as a counselor or parent liaison, should manage these early conversations and explain available services clearly and respectfully (Rivard et al., 2014).

Feedback should be gathered continuously in ways that feel natural and informal, such as brief check-ins at the end of a workshop, short surveys, or small group discussions. These moments keep caregivers at the center of planning and allow adjustments to reflect their input (Wakimizu & Fujioka, 2024). Parents who have completed training or taken part in earlier sessions can be invited to co-lead groups, suggest improvements, or help plan new activities. This example of peer-led involvement has been shown to enhance caregiver engagement and reduce stigma (Lodder et al., 2020). This model is especially critical for families from underrepresented backgrounds, who are often excluded from decision-making processes. Ensuring their voices are included fosters cultural safety and trust within the program (Wakimizu & Fujioka, 2024). When caregivers see that their input leads to real change, confidence grows and program success broadens.

Research consistently supports this approach. Gallagher et al. (1983) and Dunst and Trivette (2009) highlighted how authentic family engagement strengthens outcomes, while Chiang (2014) added that when schools build genuine partnerships with parents, especially those from culturally diverse backgrounds, families feel more confident and connected. Keeping caregiver voice as a core principle creates a shared effort where schools and families work together to support children, reduce stress, and build lasting change.

Sustainability and Scaling Strategy

Leaders should consider sustainability and scalability from the beginning to ensure the initiative's long-term impact. Integrating the program into existing district structures and staff responsibilities reduces dependence on new funding while promoting continuity (Hayes & Watson, 2013; Waqar et al., 2024). For example, schools can embed caregiver workshop

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coordination within parent engagement roles and blend peer support groups into existing school-based family programs.

Scaling should begin with a small number of pilot schools that reflect the district's range of demographics and needs. Lessons learned in these sites can guide expansion to additional schools in years two and three (Waqar et al., 2024). Cross-site collaboration can be strengthened through shared planning sessions and the use of standard evaluation tools to ensure consistent quality across schools.

Partnerships with community organizations, healthcare providers, and local parent advocacy groups are also essential. These partners can co-sponsor events, share resources, expand access to services, and reinforce trust and visibility within the community (Christi et al., 2022; Papadopoulos et al., 2018). Ongoing caregiver feedback should serve as the primary guide for the direction and priorities of the program, driving what remains relevant and effective (Gallagher et al., 1983; Wakimizu & Fujioka, 2024).

By embedding this plan into district practices, strategic piloting, and promoting caregiver voice, the Eagles Nest School District can sustain and expand this initiative in ways that are manageable and meaningful.

What Success Looks Like

For schools choosing to adopt all or parts of this plan, success can be defined by measurable improvements in caregiver well-being, confidence, and connection, not solely by the number of meetings held or services delivered (Christi et al., 2022; Meadan et al., 2010). In the short term, success should mean more families gaining timely access to respite care, mental health services, and culturally responsive information that helps them navigate daily challenges (Papadopoulos et al., 2018; Rivard et al., 2014). Caregivers may report feeling less overwhelmed and more informed about available services, and more confident in advocating for their child's needs (Chiang, 2014; Resch et al., 2010). Surveys and feedback forms can be used

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to track changes in perceived stress levels, using tools such as the PSS-10, and to measure confidence (Christi et al., 2022; Meadan et al., 2010).

Longer-term success should be reflected in stronger family-school relationships, reduced caregiver isolation, and more parents taking on leadership roles within the program (Lodder et al., 2020; Wakimizu & Fujioka, 2024). Peer support groups can become a regular part of the school community, and caregivers should know where to seek help and feel safe asking for it (Lee et al., 2023). Equity is also an indicator of success. Reaching families from different cultural and linguistic backgrounds, offering inclusive materials, and incorporating family voice into program design are essential steps (Damianakis et al., 2016; Papadopoulos et al., 2018). When caregivers feel acknowledged, respected, and valued, they are more likely to participate and stay engaged (Dunst & Trivette, 1986; Gallagher et al., 1983).

Ideally, all elements of this plan, from respite and workshops to peer mentoring and reducing stigma, should work together to create lasting change. Although caregivers may follow different paths, program leaders should ensure all families have access to the tools, connections, and support needed to take the next step forward (Meadan et al., 2010; Waqar et al., 2024). Over time, the goal is not just to reduce stress but also to create a stronger, more connected community around every child with autism in the Eagles Nest School District (Christi et al., 2022; Lodder et al., 2020).

Summary and Closing Reflection

This multi-strategy plan offers a structured and family-centered response to the real-world challenges faced by caregivers of children with ASD. It is grounded in research and shaped directly by the priorities families identified as most urgent (Christi et al., 2022; Meadan et al., 2010; Rivard et al., 2014). Each strategy addresses a different aspect of caregiver support: immediate relief through respite and mental health services, capacity-building through culturally responsive education, peer-led connection to foster belonging, and stigma reduction

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that affirms caregiver pride (Lodder et al., 2020; Waqar et al., 2024). A clear implementation timeline, defined staff roles, and a commitment to ongoing monitoring and evaluation connect these strategies (Hayes & Watson, 2013).

The plan balances structure with flexibility, allowing schools to adapt it to their unique contexts while keeping caregiver voice at the center. It was designed not as a one-time initiative but as a system that grows and improves alongside the families it serves (Damianakis et al., 2016; Papadopoulos et al., 2018). It acknowledges that lasting change comes from deliberate systems that evolve with the families they serve, not through one-time initiatives (Dunst & Trivette, 1986).

Supporting caregivers is ultimately about relationships. It requires patience, humility, and long-term commitment from schools, staff, and communities (Chiang, 2014; Gallagher et al., 1983). By implementing these research-based strategies, the Eagles Nest School District has a future course of action that recognizes caregiver strength, reduces stress, and affirms that no family must navigate the journey alone (Christi et al., 2022; Lodder et al., 2020).

As part of this project, a practical product has also been developed, The Parent Support and Resilience Plan Field Guide. This guide is designed for district leaders, school staff, and community partners. It organizes the four recommendations into clear steps, tools, and resources that can be used in everyday practice. It serves as the hands-on part of the plan, turning research into simple, usable actions for schools and families. A full description of the field guide and how it fits into the plan is provided in Section 5.

These strategies form the foundation of the PSRP. Not every component of the plan will be implemented immediately, it represents a practical and scalable framework grounded in caregiver voices and supported by research. It provides schools and districts with actionable paths to reduce stress, strengthen perceived support, and build long-term resilience among families of children with autism.

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The following section summarizes the results of the literature review, highlighting the specific caregiver needs and systemic gaps that shaped the design of the PSRP. These findings clarify why a caregiver-centered, culturally responsive approach is necessary and how it directly addresses the challenges families face.

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SECTION 4: SUMMARY OF RESULTS

Caregivers of children with autism often find themselves navigating a system that fails to consider their needs. While services for children have expanded significantly over the last two decades (Rivard et al., 2014), those who care for them continue to experience overwhelming emotional, financial, and logistical demands (Resch et al., 2010). Despite increasing evidence that caregiver stress impacts family well-being and child outcomes (Hayes & Watson, 2013), interventions are often fragmented, difficult to access, or designed without caregiver input (Meadan et al., 2010; Russa et al., 2014). Grounded in the findings discussed in Section Two, this plan emphasizes the priorities voiced by caregivers and it offers a culturally responsive and scalable approach to reduce stress, enhance perceived support, and promote long-term emotional well-being.

These results are consistent with Family Systems Theory, which suggests that stress can affect many aspects of the family system including the marriage relationship and roles as parents and siblings (Bowen, 1978; Minuchin, 1974). For example, when respite care is unavailable, caregivers may feel exhausted, which can strain the marriage, reduce patience in parenting, and leave siblings feeling neglected. Conversely, when families receive respite care, relief often improves caregiver well-being and strengthens the whole family system. The results also align with Ecological Systems Theory, which suggests that factors at multiple levels of the system have the potential to influence children and families (Bronfenbrenner, 1979, 1985). For example, when community stigma at the macrosystems level remains unaddressed, it diminishes family well-being, but district-led awareness campaigns can reverse these effects. The PSRP responds to these realities by supporting families at home while also building stronger school and community systems around them.

Building on this foundation, this section synthesizes the study's main findings and outlines the anticipated outcomes if the district implements the PSRP as designed. It highlights

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how the research question and strategies of the intervention connect to address the persistent problem of caregiver stress and the lack of meaningful support.

At the heart of this work was a simple but essential question: *Who cares for the caregiver?* Many parents raising a child with autism face high levels of stress, emotional exhaustion, and feelings of being overwhelmed (Hayes & Watson, 2013; Resch et al., 2010). A lack of support, long waits for services, stigma, and social isolation worsen this stress (Meadan et al., 2010; Papadopoulos et al., 2018). This capstone set out to explore the most beneficial types of support for caregivers and what a school district can realistically do to help.

RQ 1: What is the Relationship Between Perceived Support and Self-Reported Stress Among Caregivers of Children With Autism?

The research related to the first research question indicated that caregivers who feel supported tend to report lower levels of stress (Dunst et al., 1986; Hayes & Watson, 2013). When parents believe that help is available, trustworthy, and fits their needs, they are more able to cope with the challenges they face. In contrast, when support is missing or feels unhelpful, stress increases (Waqar et al., 2024). The PSRP's first strategy focuses on giving caregivers immediate relief, such as access to respite care and referrals to mental health counseling. These services aim to reduce high levels of stress among the most overwhelmed caregivers. The second research question builds on this by exploring the specific types of support that reduce stress most effectively.

RQ 2: Which types of support -- emotional, informational, or instrumental -- are most associated with reduced caregiver stress?

The literature pertaining to this question suggested that no single type of support works for everyone, but programs that offer emotional reassurance, practical help, and clear information tend to be most effective (Christi et al., 2022; Wakimizu & Fujioka, 2024). Parents need someone to listen to them, useful tools to manage their daily life, and information that is

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easy to understand (Al-Khalaf et al., 2013; Chiang, 2014). These findings shaped Strategy Two of the PSRP, which recommends bilingual workshops, culturally respectful communication, and parent education programs. These tools reduce feelings of confusion, worry, and isolation. To move from overall support findings to details about effective programs, the third question focused on the design of support programs.

RQ 3: What key characteristics of social support programs do caregivers identify as most beneficial in coping with stress?

The research reviewed in Section Two found that caregivers benefit most from programs that provide affirmation, validation, and understanding (Frantz et al., 2017; Riley & White, 2016). Support groups led by peers, programs that include real stories, and activities that promote belonging help parents build emotional strength. These programs have been found to reduce feelings of shame and self-blame that some caregivers carry (Gray, 2002; Papadopoulos et al., 2018). The PSRP's third strategy introduces a peer-mentoring program and small support groups led by trained caregivers. Such environments build confidence, offer emotional relief, and create lasting networks.

Together, these three research questions shaped an initiative that is practical, culturally aware, and grounded in real experiences. The PSRP translates literature into four core strategies: providing immediate relief, offering education and empowerment, building peer-led resilience, and reducing stigma (Hayes & Watson, 2013; Papadopoulos et al., 2018; Resch et al., 2010). This framework offers schools and districts a coordinated, research-based method to reduce caregiver stress, improve access to support, and affirm caregiver strengths. The plan is a system of strategies that schools can adapt and scale over time to ensure long-term sustainability and responsiveness to families' needs (Wakimizu & Fujioka, 2024).

The accompanying practitioner product focuses on the strategies that schools can realistically implement right away. Specifically, it emphasizes caregiver education, peer-led

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strategies to promote resilience, and practical steps toward immediate relief, such as referrals to respite care or counseling (Christi et al., 2022; Lee et al., 2023). These strategies are feasible for schools to coordinate with existing personnel and resources. The fourth strategy, stigma reduction, remains an essential component of the broader plan but requires community, policy, and cultural initiatives that go beyond what one school-based product can achieve (Lodder et al., 2020; Yano et al., 2015). By beginning with strategies that are practical and actionable, the product sets the foundation for schools to eventually address all four areas comprehensively. The expected result is a support system that improves caregiver well-being, strengthens family relationships, and helps schools become more inclusive and responsive.

Expected Results Over the First 12 Months

As designed, the Parent Support and Resilience Plan is intended to promote the following outcomes:

- Reduced caregiver stress, especially for those accessing respite care or mental health support, as measured by intake and follow-up stress screenings (Christi et al., 2022).
- Increased caregiver confidence and sense of control, especially for families attending educational workshops, as reflected in feedback forms and facilitator observations (Al-Khalaf et al., 2013; Chiang, 2014).
- Stronger caregiver-to-caregiver connections, leading to improved emotional support and reduced isolation, as shown through peer support group participation and engagement logs (Riley & White, 2016).
- Reduced stigma and increased caregiver pride, reflected in reports of decreased self-blame, more positive identity, and greater willingness to seek support (Corrigan & Watson, 2002; Lodder et al., 2020; Papadopoulos et al., 2018).

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- Improved school-family relationships, as demonstrated by more open communication, mutual trust, and collaborative problem-solving (Resch et al., 2010).

Although some parts of the plan may take time to develop, small but meaningful improvements in caregiver relief and connection will begin to change how families experience support. Over time, these changes can lead to improvements in student outcomes because caregiver well-being directly influences child development and educational progress (Dunst & Trivette, 2009; Meadan et al., 2010).

Critical Next Steps for Implementation and Growth

Recommended future actions:

- Every phase should include caregiver feedback, so programs remain relevant and responsive (Frantz et al., 2017).
- If outcomes are positive, peer-led models should be expanded to more schools or age groups (Lodder et al., 2020).
- Districts should advocate for policies and funding that include support programs as part of standard practice (Waqar et al., 2024).
- Partnerships with researchers or universities could assist in the evaluation of long-term results and guide improvements (Damianakis et al., 2016).

Conclusion

The central focus of this capstone is that targeted, caregiver-focused support is essential to helping children succeed. Empirical research and real-world experiences have supported this principle. The Parent Support and Resilience Plan for Families of Children with ASD is both practical and feasible. Research and the perceived needs of caregivers serve as the foundation of the program. While the goal is to equip schools to better support families of children with ASD, similar studies from other disabilities have been referenced when the same factors apply,

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and these are clearly noted in the text. This work is grounded in the idea that to take care of the child, we must also take care of the caregiver.

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SECTION 5: PRODUCT FOR PRACTITIONERS

The Parent Support and Resilience Plan Field Guide (PSRP-FG) was developed as the practitioner product of this capstone project. Building on the findings presented in Section Two and the identified needs in Section Three, the guide integrates the research on caregiver stress, perceived support, and resilience into a practitioner-ready resource. It is designed for use by school personnel, mental health providers, and community partners who support families of children with autism spectrum disorder (ASD). By grounding the product in evidence while maintaining practical focus, the PSRP-FG serves as a bridge between research and practice (Hayes & Watson, 2013; Meadan et al., 2010; Resch et al., 2010).

Goals and Rationale

The purpose of the PSRP-FG is to provide practical guidance that reduces caregiver stress and strengthens perceived support through four interconnected strategies:

1. **Immediate Relief:** short-term interventions such as referrals to respite care, counseling, and stress screenings (Christi et al., 2022).
2. **Education and Empowerment:** workshops, bilingual resources, and culturally responsive training that equip caregivers with skills and confidence (Chiang, 2014; Lee et al., 2023).
3. **Peer Leadership:** mentorship and peer support groups that foster long-term caregiver well-being (Banbury et al., 2018; Damianakis et al., 2016).
4. **Stigma Reduction and Caregiver Pride:** initiatives that challenge blame and foster pride through storytelling, campaigns, and community education (Corrigan & Watson, 2002; Lodder et al., 2020).

These strategies align with the evidence base demonstrating that emotional, informational, and instrumental supports are most effective when they are perceived as reliable and responsive (Dunst & Trivette, 1986; Wakimizu & Fujioka, 2024).

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Structure of the Field Guide

The PSRP-FG is organized around Implementation Playbooks for each strategy. Each playbook includes:

- An overview and rationale
- Step-by-step instructions for implementation
- Red Flag Callouts to help practitioners respond to urgent caregiver needs
- A Practitioner Call-to-Action summarizing essential next steps

To enhance accessibility and relevance, the field guide incorporates caregiver vignettes that reflect the lived realities documented in the research, such as financial strain, geographic isolation, work-related stress, limited respite care, and navigating complex educational systems (Resch et al., 2010; Waqar et al., 2024). The guide also provides strategies to directly address these challenges. These narratives help practitioners connect research findings to real-world contexts.

An Appendix of Tools accompanies the Implementation Playbooks, containing ready-to-use resources aligned with the PSRP strategies. These tools include caregiver stress screening forms, bilingual workshop planning templates, mentor recruitment flyers, storytelling campaign materials, social media toolkits, and quick-reference contact sheets. These resources can be customized within the Eagles Nest School District (pseudonym) while remaining adaptable for other districts.

The field guide is designed for practical use. It combines research-based recommendations with easy-to-use forms and visuals that help schools apply the strategies consistently. It also includes military-specific resources, bilingual materials, and culturally responsive practices, providing relevance to the diverse population in the Eagles Nest School District while remaining flexible for other settings.

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The field guide is intended for school administrators, counselors, special educators, family liaisons, mental health providers, and community partners. Practitioners can use it as:

1. A step-by-step implementation manual to guide rollout of PSRP strategies at the school or district level
2. A training resource to orient new staff, caregivers, and community partners to the program's goals and procedures
3. A quick-reference guide for identifying caregiver needs, coordinating support, and making timely referrals to local resources

Benchmarks and Evaluation

To ensure fidelity and effectiveness, the PSRP-FG recommends formative and summative benchmarks:

- Screening & Baseline Data: Use self-referral and validated instruments such as the PSS-10 (Cohen & Williamson, 1988) to gain insight into stress levels
- Ongoing Monitoring: Collect caregiver feedback through workshop surveys, peer observation notes, and participation records.
- Outcome Measures: Use quality-of-life assessments such as WHOQOL-BREF (World Health Organization, 1996) and conduct follow-up focus groups to track improvements in caregiver well-being.

These measures enable schools and districts to track progress, adjust strategies, and ensure interventions remain focused on caregiver needs.

Anticipated Challenges and Limitations

Implementation may be affected by time constraints, limited staff capacity, or resistance to address caregiver stress directly. Research indicates that stigma and systemic barriers often limit caregiver engagement if left unaddressed (Gray, 2002; Papadopoulos et al., 2018). The

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PSRP-FG emphasizes leadership commitment, flexibility, and cultural responsiveness as key factors for overcoming these challenges.

Conclusion

Caregivers play a central role in the development and well-being of children with ASD, yet their own needs are often left unmet. The PSRP-FG offers a structured, evidence-based response, equipping schools and community partners with practical tools to reduce caregiver stress, strengthen perceived support, and foster resilience. Grounded in research and designed for real-world application, this field guide provides a clear pathway for schools to act now, ensuring that caregivers are supported alongside their children (Hayes & Watson, 2013; Meadan et al., 2010).

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APPENDIX: CONTENT REVIEW MATRIX

Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
Al-Khalaf, A., Dempsey, I., & Dally, K. (2013). The effect of an education program for mothers of children with ASD in Jordan. Program aimed to reduce maternal stress, increase coping skills, and improve understanding of child behavior. International Journal for the Advancement of Counseling, 36(2), 175–187.	Exploratory study evaluating an education program for mothers of children with ASD in Jordan. Program aimed to reduce maternal stress, increase coping skills, and improve understanding of child behavior.	Highlights lack of parental support programs, showing stress and coping as major caregiver concerns.	Provide structured parent education programs addressing stress, coping, and child behavior understanding.	Does an education program reduce stress and improve coping skills and maternal understanding of ASD?	Pre-post design with interviews.	20 participants (10 mother-father dyads) of preschool-age children with ASD in Jordan.	Participation in education program.	Stress levels, coping skills, mother-child interaction, understanding of ASD.	Four weekly sessions (4 hours each), pre- and post-intervention interviews, standardized scales.	Significant reduction in maternal stress, increased coping, improved mother-child interaction. Mothers had higher stress and lower coping than fathers.
Banbury, A., Nancarrow, S., Dart, J., Gray, L., & Parkinson, L. (2018). Telehealth interventions delivering home-based support group videoconferencing:	Systematic review of 17 studies on group videoconferencing interventions providing education and/or social support.	Addresses accessibility of support groups for caregivers facing barriers such as distance, mobility, and isolation.	Use videoconferencing to deliver peer support and education to caregivers at home.	What is the feasibility, acceptability, effectiveness, and implementation of videoconferenced group interventions?	Systematic review with narrative synthesis.	17 included studies, sample sizes ranging from 4 to 117 participants.	Videoconferencing-based support group interventions.	Feasibility, acceptability, effectiveness, implementation outcomes.	Database searches,	Videoconferencing groups feasible and acceptable; improved accessibility, reduced isolation, similar outcomes to in-person groups. Barriers: need for IT support, occasional preference for face-to-face.

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
Systematic review. Journal of Medical Internet Research, 20(2), e25.										
Chiang, H.-M. (2014). A parent education program for parents of Chinese American children with autism spectrum disorders: A pilot study. Focus on Autism and Other Developmental Disabilities, 29(2), 88–94.	Pilot study of a 10-week parent education program for Chinese American families with children with ASD.	Addresses cultural and language barriers for immigrant caregivers and their high stress levels.	Culturally sensitive, parent-centered group education program to reduce stress and improve coping.	Does a culturally tailored parent education program reduce stress, improve confidence, and quality of life?	Pre-post group design.	Nine families (primarily mothers) of Chinese American children with ASD aged 3–11.	Participation in 10-week parent education program.	Parenting stress (PSI), parental confidence (CDQ), quality of life (WHOQOL-BREF).	10 weekly 120-minute sessions with lectures, group discussions, role-plays, parent sharing, homework assignments.	Significant reduction in parenting stress, improved parental confidence, improved quality of life (physical health and environment domains).
Christi, R. A., Roy, D., Heung, R., & Flake, E. (2022). Impact of respite care services availability on stress, anxiety,	Pilot survey-based study examining impact of respite care on stress, anxiety, and depression in military families raising children with ASD.	Highlights role of respite care as a immediate relief factor against caregiver stress in high-demand military settings.	Expand access to respite care services as part of caregiver support systems.	Is respite care availability associated with lower levels of parental stress, anxiety, and depression in military parents of	Survey-based descriptive pilot study.	119 military parents of children with ASD (Pacific Northwest, enrolled in EFMP).	Presence of respite care; demographic and family variables.	Stress (PSS-10), anxiety and depression (PHQ-4).	Anonymous surveys including demographic survey, PSS-10, PHQ-4.	Parents with respite care reported less stress, anxiety, and depression. Respite linked to improved well-being but availability limited (22.7% of families).

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
and depression in military parents who have a child on the autism spectrum. <i>Journal of Autism and Developmental Disorders</i> , 53, 4336–4350.				children with ASD?						
Damianakis, T., Tough, A., Marziali, E., & Dawson, D. (2016). <i>Therapy Online: A web-based video support group for family caregivers of survivors with traumatic brain injury. Journal of Head Trauma Rehabilitation</i> , 31(4), E1–E12.	Descriptive qualitative study evaluating benefits of a web-based video support group for caregivers of individuals with traumatic brain injury (TBI).	Demonstrates how online group models reduce caregiver stress and isolation relevant to ASD caregivers facing similar stress.	Leverage videoconferencing platforms to deliver structured emotional and social support to caregivers unable to attend in-person groups.	What are the therapeutic benefits and group processes of an online video support group for TBI caregivers?	Qualitative descriptive study with directed content analysis.	10 caregivers (8 mothers, 2 fathers) of young adults with TBI in Ontario, Canada.	Participation in online caregiver support group.	Caregiver stress, emotional expression, coping strategies, sense of isolation, acceptance, and advocacy outcomes.	10 weekly videoconferencing sessions facilitated by clinician; transcripts analyzed with NVivo; themes coded and triangulated.	Caregivers reported reduced isolation, improved coping, increased acceptance, advocacy, and mutual support. Replicated therapeutic factors of face-to-face groups.

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
Dykens, E. M., Fisher, M. H., Taylor, J. L., Lambert, W., & Miodrag, N. (2014). Reducing distress in mothers of children with autism and other disabilities : A randomized trial. <i>Pediatrics</i> , 134(2), e454–e463.	Randomized trial testing Mindfulness-Based Stress Reduction (MBSR) and Positive Adult Development (PAD) interventions led by peer-mentors for mothers of children with disabilities.	Directly addresses caregiver stress and mental health, showing effectiveness of adult-focused interventions outside of child-centered programs.	Implement evidence-based mindfulness and positive psychology programs using trained peer-mentors for caregivers.	Do MBSR and PAD reduce stress, depression, and anxiety in mothers of children with disabilities, and are there differential effects by child diagnosis (ASD vs other)?	Randomized controlled trial.	243 mothers of children with ASD (65%) or other disabilities (35%).	Type of intervention (MBSR vs PAD).	Stress (PSI), depression (BDI), anxiety (BAI), insomnia, life satisfaction, psychological well-being.	6-week group interventions (1.5 hours/week) led by trained peer mentors, with six assessment points up to 6 months post-intervention.	Both MBSR and PAD significantly reduced stress, anxiety, depression, and improved sleep/life satisfaction. MBSR yielded stronger improvements in anxiety, depression, and sleep. Peer mentors were effective facilitators.
Frantz, R., Hansen, S. G., & Machalicek, W. (2017). Interventions to promote well-being in parents of children with autism: A systematic review. <i>Journal of Autism</i>	Systematic review of 41 studies examining interventions designed to improve parental well-being (stress, depression, self-efficacy) among parents of children with ASD.	Highlights the growing evidence base for caregiver-focused interventions and identifies effective formats (CBT, mindfulness, psychoeducation).	Expand evidence-based, multicomponent interventions directly targeting parent stress and mental health.	What types and formats of interventions have been used? Which are most effective? How strong is the evidence base for parent-focused interventions?	Systematic review using PRISMA with coding of participant/intervention characteristics and quality standards.	41 studies; 2147 parents (75% mothers). Children aged 21 months–23 years (mean age ~5).	Type of intervention (behavioral, psychoeducational, mindfulness, other).	Parent stress, depression, self-efficacy.	Database searches (ERIC, PsycINFO, Medline), screening, coding, quality appraisal using WWC standards.	CBT and mindfulness consistently effective in reducing stress and depression. Multicomponent interventions stronger than single-strategy programs. Evidence base growing but still uneven.

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
and Developmental Disorders, 5(1), 58– 77.										
Gray, D. E. (2002). 'Everybody just freezes. Everybody is just embarrassed': Felt and enacted stigma among parents of children with high functioning autism. <i>Sociology of Health & Illness</i> , 24(6), 734–749.	Qualitative interview study exploring stigma experiences of parents of children with high-functioning autism in Australia.	Introduces the concept of courtesy stigma, showing how stigma affects both children and caregivers and intensifies stress.	Develop stigma-reduction initiatives that address both felt and enacted stigma toward families.	What types of stigma (felt vs enacted) do parents of children with high-functioning autism experience, and how do they cope?	Qualitative, semi-structured interviews with thematic analysis.	53 parents (32 mothers, 21 fathers) of 33 families; children ages 5–26.	Parent role and child symptom type (aggressive vs passive).	Experiences of stigma (felt vs enacted).	Semi-structured interviews (1–4 hours) coded for stigma themes and coping strategies.	Most parents reported stigma; mothers more likely to experience enacted stigma. Stigma linked to child aggression. Parents used selective disclosure, restricted encounters, and affiliation cycles as coping strategies.
Hayes, S. A., & Watson, S. L. (2013). The impact of parenting stress: A meta-analysis of studies comparing the experience of parenting	Meta-analysis comparing parenting stress in parents of children with ASD to those of typically developing children and children with other disabilities.	Provides quantitative evidence that parenting children with ASD is uniquely stressful compared to other groups.	Design interventions targeting parenting stress specifically for ASD caregivers, beyond generic disability supports.	Do parents of children with ASD experience higher parenting stress compared to parents of TD children or other disabilities?	Meta-analysis of 15 comparative studies.	15 studies; mix of mothers and fathers of children with ASD, and other disabilities.	Child diagnostic group (ASD, TD, other disability).	Parenting stress (measured via PSI, QRS, FI, etc.).	Database and reference searches; inclusion of studies with validated stress measures; effect sizes calculated.	Parents of children with ASD reported significantly higher stress than both TD and other disability groups. Stress linked to ASD-specific behaviors (social communication deficits,

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
										stress in parents of children with and without autism spectrum disorder. Journal of Autism and Developmental Disorders, 43(3), 629–642.
Lee, J.D., Terol, A.K., Yoon, C.D., & Meadan, H. (2023). Parent-to-parent support among parents of children with autism: A review of the literature. <i>Autism</i> , 28(2), 263-275.	A scoping review of 25 studies examining parent-to-parent (P2P) support among parents of children with autism. The review identified delivery models (support groups, mentor-mentee, and cascading models), outcomes, and social validity. P2P support was shown to provide emotional, informationa	Addresses the isolation and stress experienced by caregivers of children with ASD and emphasizes peer mentorship as a protective factor for resilience. Highlights the potential of P2P models to empower caregivers and strengthen perceived support within communities.	Implement structured peer mentorship and cascading training models in schools to expand caregiver networks, increase emotional support, and enhance coping skills among families of children with ASD.	What is the current research evidence on parent-to-parent (P2P) support among parents of autistic children, and what are its characteristics, outcomes, and stakeholder perceptions?	Scoping review guided by Arksey and O'Malley's (2005) framework and PRISMA guidelines.	25 studies involving 141 parent mentors and 747 parent mentees across multiple countries (including the United States, Canada, China, and Colombia).	P2P support models: support groups, mentor-mentee, and cascading (train-the-trainer) models.	Caregiver outcomes including stress reduction, empowerment, satisfaction, social connection, and skill acquisition.	Five-stage scoping review (identifying research questions, selecting studies, charting data, synthesizing results).	P2P interventions consistently reduced caregiver stress, improved coping, and increased perceived social support. Cascading models were feasible and effective for diverse and low-resource populations. Parents reported high satisfaction, stronger sense of belonging, and reduced isolation.

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
	I, and practical benefits, particularly for underserved families.									
<p>Lodder, A., Papadopoulos, C., & Randhawa, G. (2020). SOLACE: A psychosocial stigma protection intervention to improve the mental health of parents of autistic children—A feasibility randomized controlled trial. <i>Journal of Autism and Developmental Disorders</i>, 50, 4477–4491.</p>	<p>Feasibility randomized controlled trial testing SOLACE, an 8-week stigma-protection intervention for parents of recently diagnosed autistic children.</p>	<p>Directly addresses stigma's impact on caregiver mental health and tests an intervention to reduce affiliate stigma and distress.</p>	<p>Implement stigma-protection programs combining psychoeducation, cognitive restructuring, and compassion-focused strategies.</p>	<p>Is SOLACE feasible, acceptable, and effective at improving caregiver mental health and reducing stigma effects?</p>	<p>Feasibility RCT with mixed methods (quantitative measures and focus groups).</p>	<p>17 parents (9 intervention, 8 control) of children ≤10 years recently diagnosed or awaiting ASD diagnosis, UK.</p>	<p>Group assignment (SOLACE vs control).</p>	<p>Mental health, stigma, self-esteem, self-compassion, positive meaning in caregiving, social support.</p>	<p>8-week group program, blended face-to-face and online. Pre-, post-, and 6-week follow-up assessments; focus groups.</p>	<p>High feasibility and adherence. SOLACE group showed significant mental health improvements vs control. Positive trends for stigma, self-esteem, self-compassion. Parents reported acceptability and value of strategies.</p>
<p>Meadan, H., Halle, J. W., & Ebata, A.</p>	<p>Comprehensive literature review</p>	<p>Synthesizes evidence that ASD places unique stress</p>	<p>Develop family-centered interventions</p>	<p>What stressors do families of children with</p>	<p>Systematic literature review of</p>	<p>57 peer-reviewed studies involving</p>	<p>Not applicable—review study (family</p>	<p>Stress outcomes, coping, quality of</p>	<p>Database and hand search; synthesis</p>	<p>Parents of children with ASD report higher stress</p>

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
T. (2010). Families with children who have autism spectrum disorders: Stress and support. Exceptional Children, 77(1), 7–36.	(2000–2007) of 57 empirical studies examining family stress and supports in ASD contexts.	across family subsystems and highlights coping/support needs.	targeting marital, parental, and sibling subsystems with both formal and informal supports.	ASD experience across subsystems? What supports are used and effective?	empirical studies.	parents and siblings of children with ASD.	subsystem context).	life, well-being.	organized by family subsystems and coping/support domains.	and lower well-being vs parents of TD or other disabilities. Mothers more stressed than fathers. Social support buffers stress. Sibling outcomes mixed (some negative, some positive).
Papadopoulos, C., Lodder, A., Constantinou, G., & Randhawa, G. (2018). Systematic review of the relationship between autism stigma and informal caregiver mental health. Journal of Autism and Developmental Disorders, 49, 1665–1685.	Systematic review of 12 studies (n=1442 caregivers) investigating autism stigma's impact on informal caregiver mental health.	Provides robust evidence that stigma consistently worsens caregiver mental health, showing stigma as a core issue.	Address stigma through multi-level interventions and strengthen caregiver resilience via self-compassion and social support.	How does autism-related stigma (public, courtesy, affiliate) impact caregiver mental health across cultures?	Systematic review with narrative synthesis (qualitative and quantitative studies).	12 studies; 1442 informal caregivers across East Asia, Middle East, Western contexts.	Stigma type (public, courtesy, affiliate).	Caregiver mental health (depression, anxiety, distress, well-being).	Database searches, screening, appraisal; narrative synthesis organized by cultural setting.	All studies reported stigma negatively impacted caregiver mental health. Identified moderators: self-esteem, self-compassion, social support, culture, time since diagnosis.

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
Resch, J. A., Mireles, G., Benz, M. R., Grenwelge, C., Peterson, R., & Zhang, D. (2010). Giving parents a voice: A qualitative study of the challenges experienced by parents of children with disabilities. <i>Rehabilitation Psychology, 55</i> (2), 139–150.	Qualitative study using focus groups to identify challenges experienced by parents of children with disabilities.	Highlights mismatch between caregiver needs and available services, linking stress to systemic/environmental barriers.	Develop family-centered policies and interventions that address environmental and systemic barriers (Information, finances, inclusion).	What are the primary stressors and challenges parents of children with disabilities face, and what supports do they identify as needed?	Qualitative study with focus groups.	40 parent caregivers from seven communities in a southwestern U.S. state.	Parent caregiving role and context.	Perceived stressors, barriers, needed supports.	Focus groups; thematic analysis with data reduction and cross-site validation.	Four themes: (1) access to information/services, (2) financial barriers, (3) school/community inclusion, (4) family support. Challenges due largely to lack of environmental supports rather than inherent caregiving tasks.
Riley, T., & White, J. (2016). Developing a sense of belonging through engagement with like-minded peers: A matter of	Qualitative case study of gifted students, parents, and teachers exploring how peer connectedness fosters belonging and educational equity.	Highlights importance of peer belonging and shared experiences, reinforcing value of peer-led support for ASD caregivers.	Facilitate peer connections and belonging-focused interventions to reduce isolation among caregivers.	How do gifted students and their families describe belonging developed through like-minded peer engagement?	Qualitative case study with thematic analysis.	Gifted students, their parents, and teachers in case study settings (New Zealand).	Peer engagement setting.	Sense of belonging, equity, inclusion outcomes.	Interviews, focus groups, observations; thematic coding of experiences.	Belonging emerged when students and families connected with like-minded peers; reinforced equity and well-being through

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
equity. Gifted Education International, 32(3), 248–261.										shared experience.
Rivard, M., Terroux, A., Parent-Boursier, C., & Mercier, C. (2014). Determinants of stress in parents of children with autism spectrum disorders. <i>Journal of Autism and Developmental Disorders</i> , 44(7), 1609–1620.	Quantitative study of stress in 118 families of young children with ASD at onset of Early Intensive Behavioral Intervention (EIBI) in Québec.	Demonstrates multiple predictors of caregiver stress, including child factors and service wait times, relevant to systemic intervention design.	Reduce waiting times, tailor supports to symptom severity and family characteristics, and provide early stress interventions for fathers and mothers.	What child, parent, and service-related factors predict maternal and paternal stress in families with young children with ASD?	Quantitative, cross-sectional, correlational study with hierarchical regression analyses.	118 fathers and 118 mothers of children aged 2–5 with ASD.	Child's age, gender, IQ, adaptive behaviors, severity of ASD symptoms, waiting time for services, maternal education.	Parenting stress (PSI-SF scores, subscales).	Parental questionnaires (PSI-SF, ABAS-II), child assessments (CARS, WPPSI-III); statistical analyses.	Both parents' stress linked to child factors and waiting times. Fathers reported significantly higher stress than mothers. Paternal stress predicted by child's gender and symptom severity; maternal stress linked to child age and adaptive behaviors.
Russa, M. B., Matthews, A. L., & Owen-DeSchryver, J. (2015). Expanding supports to	Conceptual and practice-focused article outlining family-	Focuses on family needs and provides useful supports through	Adopt PBIS, Parent-to-Parent, Medical Home, Family Navigator	What family-centered supports and models are most effective in addressing family stress	Conceptual review of best practice models and strategies.	Not empirical — practice models synthesized from	Application of family-centered models (PBIS, PTP, Medical	Family stress, parent satisfaction, service access,	Synthesis of evidence-based practices and family-centered frameworks.	Identified family needs: quality information, coordinated services,

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
improve the lives of families of children with autism spectrum disorder. Journal of Positive Behavior Interventions, 17(2), 95–104.	centered approaches and models to reduce stress and improve supports for ASD families.	different stages of development.	models to meet evolving family needs.	and unmet needs across the lifespan of children with ASD?		literature and case applications.	Home, Navigator).	child/family outcomes.		respite, advocacy, community involvement, transitions. Family-centered models improve satisfaction and outcomes when implemented collaboratively.
Wakimizu, R., & Fujioka, H. (2024). Social support needs of caregivers rearing children with severe motor and intellectual disabilities: A nationwide survey in Japan. Journal of Intellectual Disability Research, 68(2), 145–160.	Large-scale cross-sectional survey of caregivers to identify unmet social support needs when raising children with severe motor and intellectual disabilities (SMID).	Shows extent of caregiver support needs beyond ASD, demonstrating systemic service gaps and reinforcing importance of multidisciplinary approaches.	Expand social and respite services, strengthen collaboration across systems, provide legal/administrative reforms and caregiver-focused services.	What social support needs do caregivers of children with SMID identify as most urgent and unmet?	Cross-sectional nationwide survey.	1,176 caregivers of children with SMID in Japan.	Caregiver demographics, child characteristics, service context.	Identified support needs (seven categories).	Structured questionnaire survey distributed nationwide; thematic grouping of needs.	Seven categories of needs: (1) expansion of facilities/services, (2) respite, (3) legal/administrative reforms, (4) welfare equipment, (5) school/community collaboration, (6) medical/nursing cooperation, (7) caregiver services. Emphasized systemic barriers and gaps.

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Citation	Study Description	Connection to PoP	Proposed Solution	Research Questions/Purpose	Design	Sample/Participants	Ind. Variables	Dep. Variables	Procedures	Results
Waqar, S., Fatima, T., Ali, S., & Rehman, A. (2024). Prevalence and predictors of stress among caregivers of children with developmental disorders: Evidence from Pakistan. <i>Frontiers in Psychology</i> , 15, 1432100.	Cross-sectional study examining stress levels and predictors among mothers of children with developmental disorders in Pakistan.	Highlights findings from low-resource settings where caregivers face severe stress, providing insights relevant to ASD caregiving.	Develop targeted interventions considering sociodemographic predictors (education, income, family size, diagnosis timing).	What is the prevalence of stress among caregivers, and what demographic/clinical factors predict stress severity?	Quantitative cross-sectional survey.	200 mothers of children with developmental disorders.	Caregiver age, child age, number of children, time since diagnosis, education, income.	Perceived stress (PSS-10 scores).	Administered Perceived Stress Scale (PSS-10); regression analyses of predictors.	Mean stress score 31.9 (severe stress). Positive predictors: caregiver age, child age, # of children, time since diagnosis. Protective: higher education, higher income. Highlights urgent intervention needs.
Yanos, P. T., Lucksted, A., Drapalski, A. L., Roe, D., & Lysaker, P. (2015). Interventions targeting mental health self-stigma: A review and comparison. <i>Psychiatric Rehabilitation Journal</i> , 38(2), 171–178.	Narrative review comparing six self-stigma interventions: Healthy Self-Concept, Self-Stigma Reduction Program, Ending Self-Stigma (ESS), Narrative Enhancement and Cognitive Therapy (NECT), Coming Out Proud, and Anti-Stigma PhotoVoice.	Offers models that can be adapted for ASD caregivers facing affiliate/self-stigma, highlighting mechanisms of action and outcomes.	Adapt group-based stigma interventions (psychoeducation, CBT, narrative, peer-led) for ASD caregiver populations.	What interventions exist for reducing mental health self-stigma, and how do their mechanisms and outcomes compare?	Narrative review of published intervention studies.	Six programs reviewed; populations included adults with severe mental illness across multiple countries.	Type of intervention (Healthy Self-Concept, SSRP, ESS, NECT, COP, PhotoVoice).	Self-stigma, self-esteem, hope, empowerment, social withdrawal.	Database searches; inclusion of studies explicitly targeting internalized stigma; synthesis of structure, format, mechanisms, outcomes.	All six approaches showed promising results. Common features: group format, psychoeducation, CBT, narrative work. Outcomes: reduced self-stigma, improved self-esteem, empowerment, hope. Evidence mostly from small-to-medium RCTs; larger trials ongoing.

Appendix A

Measurement Tools

Instrument	Description	Scoring	Reliability/Validity	Example Use in Caregiver Research
<p>Perceived Stress Scale-10 (PSS-10)</p>	<p>10-item self-report questionnaire measuring perceived stress over the past month. Items reflect feelings of unpredictability, lack of control, and overload.</p>	<p>5-point Likert scale (0 = never to 4 = very often). Total scores range 0-40. Higher scores = greater stress.</p>	<p>Strong internal consistency ($\alpha = .78-.91$). Widely validated across populations, including caregivers of children with ASD.</p>	<p>Christi et al. (2022) used PSS-10 to assess caregiver stress in military families. Meadan et al. (2010) referenced its reliability in family systems research.</p>
<p>World Health Organization Quality of Life-Brief Version (WHOQOL-BREF)</p>	<p>A 26-item questionnaire assessing four domains: physical health, psychological well-being, social relationships, and environment.</p>	<p>Uses a 5-point response scale; domain scores are transformed to a 0-100 scale. Higher scores reflect better quality of life.</p>	<p>Demonstrates strong construct validity and sensitivity to change in ASD-related interventions.</p>	<p>Chiang (2014) used the WHOQOL-BREF to measure caregiver well-being in culturally responsive parent education programs. Christi et al. (2022) employed it to evaluate mental health outcomes.</p>

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