

The Families of Children With Developmental Disabilities: Coping and Acceptance

By

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Abstract

This capstone project uses a phenomenological literature review to explore how families who have a child with a developmental disability cope and find acceptance with the diagnosis. There is an emotional and structural shift that affects the family unit once they receive a diagnosis of their child having a developmental disability. This project draws on theoretical frameworks such as family systems theory, ecological systems theory, ambiguous loss theory, the meaning-making model, and the family resilience framework to examine the emotional, relational, and cultural dimensions within the family unit. Key findings highlight that acceptance is shaped through resiliency, meaning-making, cultural and spiritual values, and support systems. Gaps in the literature include a lack of support for siblings, culturally responsive practices, and families facing systemic barriers such as stigma and inadequate services. The family resilience and meaning-making support model is adapted as a strength-based, inclusive, and culturally informed model for practitioners to utilizing their services.

Keywords: developmental disability, meaning-making, coping, resilience, acceptance

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Chapter One: Introduction

A child's development is comprised of various components such as emotional, physical, and social growth. The family unit is considered the foundation for the child's developmental period and the support that is needed throughout the lifespan. For a family that has a child with a developmental disability, there is often a disruption in the family system as there are more responsibilities placed on the family members to support their child's development. In this capstone, the American Psychiatric Association (2022) refers to developmental disability as neurodevelopmental conditions developed at birth and/or childhood, which persists across the lifespan, affecting intellect, communication, social, and adaptive functioning. In accordance with the *Diagnostic and Statistical Manual of Mental Disorders* (5th ed., text rev.; *DSM 5-TR*; as cited in American Psychiatric Association, 2022), neurological developmental conditions also include intellectual developmental disorder (IDD) such as autism spectrum disorder (ASD) and attention deficit hyperactivity disorder (ADHD). The onset of this condition is during the developmental period and the impairments impact adaptive, intellectual, social, executive, and/or occupational functioning (American Psychiatric Association, 2022). Based on the literature, a conclusion may be drawn that having more responsibility often opens doors to experiencing a variety of emotions that the family must navigate (Bakula et al., 2024; Burton et al., 2017).

Acceptance is a concept in which families undergo over time to work towards reducing their emotional responses and acknowledging their child's disability (Bakula et al., 2024). This capstone project will explore how families find acceptance and meaning in their child's diagnosis. There will also be a discussion on how coping mechanisms are used for families to cope with the stressors associated with the lifestyle changes that arise. Chapter three will

synthesize the studies to create an action plan of how practitioners can support families in understanding each other and work towards finding acceptance.

This first chapter provides an overview of the topic and how families are impacted by developmental disabilities. I will also discuss how this topic contributes to the field of psychology and the overall purpose of this review. A positionality and reflexivity statement will also be shared to provide insight into my previous perspectives on this topic, along with identifying any biases I have prior to conducting research. The purpose of this reflection is for the reader to understand my stance on this topic and why it is personal and meaningful for me.

Overview of the Topic

For this capstone paper, the term developmental disability will be used as an umbrella term for neurodevelopmental disorders including IDD, ASD, and ADHD, as indicated in the *DSM 5-TR* (American Psychiatric Association, 2022). The World Health Organization's (2025) *International Statistical Classification of Diseases and Related Health Problems* (11th ed.; *ICD-11*) uses a different terminology such as neurodevelopmental disorders, whereas the Centres for Disease Control and Prevention (2024) use the term developmental disability. Canadian policies and services use the umbrella term developmental disability; therefore, this capstone project will use developmental disability while also acknowledging the overlaps and variations in definitions and terms across all systems.

A recent statistic from 2022 shows that approximately 1.5% of the Canadian population is diagnosed with a developmental disability (McDiarmid, 2024). This statistic only accounts for individuals over 15. Among the 1.5% of individuals, 77% stated that their families were a major source of support. This statistic highlights the importance of familial support for individuals with developmental disabilities. The impact on families upon receiving the diagnosis shifts their

worldview. For instance, families may experience emotional, relational, and other stressors associated with the news. Therefore, not only are the families a source of major support for the individual, but they also must work on building a network to support their family member.

The Centers for Disease Control and Prevention (2024) define developmental disability as a condition that impacts physical, learning, language, or behaviour, usually through impairments in day-to-day functioning. Examples of this include diagnoses such as ASD, Down syndrome, Fragile X syndrome, and others, which impact physical and mental impairments. These conditions require the individual to receive long-term support for their physical, psychological, and educational needs. The literature states that over the years, support and advocacy for individuals with developmental disabilities have expanded, and the government has provided additional funding for adult developmental services. However, there is a gap in providing emotional support for the caretakers of individuals with disability. There is an impact on the family of those receiving the diagnosis, not only emotional, but also a shift in day-to-day living (Malka & Fine, 2024; Udhmani et al., 2023).

Receiving a developmental disability diagnosis causes emotional distress for the family to process the news they received and how to manage and a shift in their lifestyle around their child with differing abilities compared to neurotypical children (Bakula et al., 2024). Mahat-Shamir and Huri-Rotman (2024) found that while some families may only feel the initial shock, others tend to experience a prolonged effect of adjusting. This emotional process may include feelings of guilt, grief, anxiety, and isolation (Mahat-Shamir & Huri-Rotman, 2024). The underlying reason for the ongoing emotional turmoil is finding acceptance of the changes associated with their child's diagnosis (Bakula et al., 2024; Mahat-Shamir & Huri-Rotman, 2024). Acceptance is influenced by resiliency, culture, and support. This capstone will further

explore the path towards acceptance and understanding how families cope and find meaning in their challenges beyond the emotional impact of their struggles.

Not only do parents experience the stress from caring for a child with a developmental disability, but siblings also experience stress from the diagnosis. However, the impact on siblings may be less visible as indicated by some research (Kilmer et al., 2010). There is a shift in role expectations and enhanced responsibility in the children for sharing the caretaking roles. Research by Kilmer et al. (2010) highlights some emotions siblings experience such as anxiety, depression, guilt, fear, resentment, and isolation. This capstone will explore the impact of a family member's developmental disability on siblings.

The concept of meaning-making and acceptance is indicated in the literature by benefiting families in reducing their emotional responses to receiving a lifelong developmental diagnosis for their child. A study by MacPhee et al. (2015) found that families who engage in more meaning-making develop stronger methods of coping and resilience in navigating stressful events and provide families the opportunity to find purpose when faced with a challenge. By creating purpose, families gain a sense of control and hope. Finding acceptance supports families in creating a positive environment for their child to strengthen their developmental growth and family connection (MacPhee et al., 2015). This capstone will further explore the meaning-making experiences of how families accept and find meaning following the diagnosis of their child with a developmental disability

It can take time for families to develop adaptive coping strategies and make meaning out of their situation. There are a few protective factors that support adaptive coping, such as cognitive reframing, faith and spirituality, partaking in support groups, and therapy (Campodonico et al., 2021). On the other hand, some factors may hinder acceptance and the

meaning-making experience (Campodonico et al., 2021). A few maladaptive coping mechanisms include denial, emotional withdrawal, and isolation. Resilience and finding meaning are correlated with each other (Campodonico et al., 2021; Peleg & Peleg, 2024). Research indicates that families who report higher rates of well-being also find purpose in moments of stress easily (Peleg & Peleg, 2024). Studies also show that coping and acceptance are shaped through cultural experiences and expectations (Luong et al., 2020). This capstone will critically analyze the adaptive and maladaptive coping mechanisms associated with families finding meaning and acceptance of their child.

Purpose Statement

The purpose of this capstone project is to explore acceptance and meaning-making in families who have a child with a developmental disability and how they navigate and cope through the various stressors and changes that occur within the family dynamic and individual roles. Psychological and relational processes of the family experience is examined to understand how families construct meaning and reorganize family dynamics and identity as a result of their child's diagnosis. The project further examines the family dynamics and meaning-making process through coping strategies that contribute to the life changes associated with the child's diagnosis. The research question that this capstone aims to answer is: How do the families of children with a developmental disability cope and find acceptance with the diagnosis?

This topic is significant within the field of psychology because there is a lack of attention placed on the emotional needs of caregivers who have a child with a developmental diagnosis. Caregivers and siblings are seen as second and not directly included in the clinical intervention process with the child (Su et al., 2022). Thus, families may experience a sense of isolation when navigating through a range of emotions such as grief, guilt, cultural stigma, and role disruption.

Su et al. (2022) further highlight that when caregivers' well-being is neglected, there is an increase in distress and a disruption in family dynamics. Without adequate support, the functionality of family's cohesiveness becomes affected.

This review will discuss several themes that guide the structure. The themes include: identifying emotional responses once receiving the diagnosis, such as guilt, grief, and denial; the families' process of meaning-making and reconstruction of family identity; adaptive and maladaptive coping strategies; how culture and societal beliefs influence acceptance; and the underrepresentation of siblings and their lived experiences. In chapter three, future recommendations and practical insights are outlined for clinicians and support workers who are working with families navigating their child's developmental disability.

Theoretical Framework

There are several theoretical frameworks which guide the research question: How do families find acceptance and cope with their child receiving a diagnosis of a developmental disability? This capstone project is grounded in frameworks such as the family resilience framework by Froma Walsh (2003) and the meaning-making model developed by Crystal L. Park and Susan Folkman (2013). This research is also grounded in family systems theory by Murray Bowen (1978), ecological systems theory by Bronfenbrenner (1979), and ambiguous loss theory by Pauline Boss (1999). Although many of these theories are over 20 years old, they still remain influential in today's counselling literature and practices. Contemporary research examines and applies these theories consistently to understand family adaptation, systemic stressors and barriers, and resiliency (Carr, 2019; Walsh, 2016). Despite the longevity these frameworks have been presented for, their value and influence in current applied practice

remains the same. These theoretical frameworks provide a multidimensional lens that will be beneficial when analyzing the literature.

Walsh developed the family resilience framework in 2003. This framework provided a strength-based perspective in the field of psychology on how families face adversity (Walsh, 2003). Walsh emphasizes a family's belief systems, organization, and communication within the family unit. The family resilience framework was used in this capstone to conceptualize how resilience appears in families when faced with stress and transform their experiences to create a new family system that is functional. Although this model was created as a broad, systemic model and a general clinical, conceptual tool for families facing stressors, the framework can be applied to developmental disability as it supports counsellors in identifying protective factors, including shared belief systems and problem-solving. Walsh states in the literature that this framework can be applied to various populations, one of which includes the context of disability (Ungar, 2013; Walsh, 2003). A limitation to note within the literature is that the research for resiliency underrepresents culturally diverse families (Ungar, 2013).

The meaning-making model was developed by Crystal L. Park in 2010. Their model is rooted in the exploration of how families and individuals make sense of stressful and/or traumatic experiences. There are two distinctions between meaning in this system: global, which refers to core beliefs and values, and situational, which refers to the interpretation of a specific event. The meaning-making model states that distress occurs when global meaning and situational meaning are misaligned (Park, 2013). Park developed this model specifically for individuals who were facing serious illnesses and trauma, with a focus on belief systems and spiritual influences (Park, 2013). The limitations of this model as depicted in the literature includes methodological concerns, such as a lack of longitudinal follow-ups and risks of

maladaptive rumination of meaning-making if individuals cannot find meaning in their experience (Park, 2013). This capstone reviewed the literature in this framework by understanding how families reframe their expectations and reconstruct meaning of their child's diagnosis of a developmental disability.

Family systems theory was developed by Murray Bowen in 1978 and focuses on the family as an emotional unit as members of the family interact with each other and how that interaction influences their nervous systems (Watson, 2012). Bowen discussed a disruption within the family's equilibrium when they receive the news of their child having a developmental disability. Family members are required to shift in their caretaking roles, expectations of the future, and how they interact with each other (Watson, 2012). Although family systems theory was developed in the 1970s, it is still relevant and used in today's practice (Brown & Errington, 2024). In contemporary counselling, it is still used to understand a diverse set of families such as blended families, immigrant families, and one with a child with a developmental disability. The diverse use of family systems theory highlights the flexibility of using this approach in current practices. The initial understandings of how family members interact and communicate and their roles are all still applicable in today's family structures (Brown & Errington, 2024). This framework was used throughout this capstone project to form an understanding of how families re-invent balance within the family unit.

Ecological systems theory was created by Bronfenbrenner in 1979 with the intention of understanding the broader family system from an environmental standpoint (Guy-Evans, 2024). The centre of this model includes three systems, microsystems, exosystems, and macrosystems, which shape families' lived experiences. For instance, what is included in these systems would be family and schools, healthcare systems, and cultural beliefs and policies (Guy-Evans, 2024).

The ecological systems theory was used in this project to analyze how external factors influence the family's adaptation process either through support or hindering their experience.

Pauline Boss developed ambiguous loss theory in the 1970s with the intent to understand the emotional response that is present when there is a loss that is unclear or lacks closure occurs (Boss, 2007). This theory highlights a family's grief process for their child's future and how they navigate feelings related to societal expectations and child development. The family's grief for their child's future and their change in lifestyle and perception is often invisible to others however present throughout their journey (Boss, 2007). Ambiguous loss theory support families in acknowledge their feelings of loss and sadness while remaining strong for their child.

Integrating these theories together provides insight into family adaptation. The theories highlight relational patterns in the family unit, systemic influences, grief and loss processes, resiliency, and meaning-making, which shapes the concept of acceptance. The capstone's research question becomes addressed by integrating the frameworks discussed.

Methodology

This capstone paper applies a qualitative, phenomenological approach to exploring the lived experiences of families with children with developmental disabilities. A phenomenological approach was chosen for this topic as it is focused on understanding how families and individuals make sense and give meaning to significant life events, such as a child receiving a diagnosis of a developmental disability, and how families cope and work towards acceptance. Phenomenology provides an in-depth examination of families assigning meaning to their experiences (Neubauer et al., 2019). The interactions influence the families emotional, relational, and functional responses to their child being diagnosed with a developmental disability.

This paper gathers literature and synthesizes the research from peer-reviewed qualitative studies. A phenomenological literature review consolidates findings from various sources, highlighting themes and emotional processes that support the journey towards acceptance (Neubauer et al., 2019). The goal of using a phenomenological approach is to gain a deeper understanding of the internal and external coping mechanisms that families use to create meaning of their child's diagnosis with a developmental disability. Contextual factors are also identified using this approach including culture, resilience, and support systems.

The literature research was collected from academic sources such as PSYCInfo, PubMed, and Google Scholar. Articles were chosen based on certain criteria. For instance, articles had to be published in peer-reviewed journals; have a focus on families with children with a developmental disability that discussed acceptance, meaning-making, and/or coping concepts; and to have been published within the last 10 years. However, the theories integrated into the research used are over 20 years old and still applicable in today's practices. For instance, as indicated by Brown and Errington (2024), family systems theory appears in current practice as it still identifies how a family member's emotional experience impacts the entire family unit. Ecological systems theory is still present in today's research as it focuses on families who have a child with a developmental disability and provides a lens on capturing how systemic inequities shape the family's experiences and impact outcomes (Su et al., 2022). Boss' (2007) ambiguous loss theory remains a critical component in contemporary psychology as non-finite grief has become an ongoing concept becoming more widely recognized in today's literature. Current research applies non-finite grief towards populations experiencing chronic illness and other disabilities (Boss, 2007). Articles that did not meet these criteria were not included in the capstone literature review. Attention was placed on the quality of the methodology, participant

demographics, and cultural context. The articles were synthesized using thematic analysis to identify reoccurring patterns. Prior to finalization, a City University faculty professor, Dr. Heidi Nichilo, and a second faculty reader oversaw, proofread, and edited the paper.

Contribution to the Field

The analysis of the literature contributes to the field of counselling psychology by highlighting the significance of how families are impacted by a child having a developmental disability and how the family copes and finds acceptance of the diagnosis and the lifestyle changes that occur with it. There is an emphasis on providing individuals with disability support and access to services that enhance their well-being and overall quality of life. Support services include advocating for clients, obtaining government funding, providing access to therapeutic services, and fostering a social network. A gap in the field is providing emotional support to the caregivers and family members of the person with a developmental disability. This capstone intends to provide practitioners with knowledge and tools to support families struggling to navigate their child's diagnosis.

Reflectivity and Positionality Statement

My personal connection to this topic led me to seek out opportunities in professional settings to provide support and expand my knowledge and awareness of the gaps. When I was 11 years old, my younger brother was born, and he was diagnosed with Down syndrome. Although I was young when he was born, my family and I adapted to working with his disability by submerging ourselves into being his support system and gathering professionals to be included on his support team. His place in my family influenced me to be in the helping profession. I initially began by working with children on the autism spectrum as a Behavioural Interventionist. My work with children with a developmental disability expanded my knowledge

in understanding behavioural complexities and navigating the system to support children with a disability. I also began to work closely with the families and provided additional lay counselling, as the parents often presented as being worried and overwhelmed with navigating their child's complexities. It was at this moment that I recognized the gap in support provided to families and noticed the differences in some families providing more emotional support and others struggling, leading to instances of denial of their child's capabilities.

As a heterosexual, East Indian, Canadian-born female, I recognize that I am influenced and surrounded by both collectivist and individualist cultures that have shaped my worldview. Although I grew up in a collectivist household, I was educated and socialized in an individualistic society. This experience has created a bias in me with this topic by emphasizing familial ties and support when caring for a person with differing abilities. In collectivist cultures, there is an emphasis placed on supporting family and community members. On the other hand, I also recognize that some members of this culture do not support individuals who present differently than they do, and they look down on people who have a disability. This part of my bias creates frustration with individuals who are unwilling to accept someone different from them. To minimize my biases in influencing this research, I will be critically analyzing different articles highlighting various cultural populations to challenge my inherent beliefs. Finding opposing articles as I gather information will support me in expanding my worldview and understanding different ways of thinking. Each family and individual have their own way of thinking and views that lead their decision-making.

My goal for this research analysis is to conduct a critical analysis into how families cope with and find meaning in their child's disability and what practitioners can do to support families

with barriers to acceptance. By doing so, I believe that extended outcomes can create harmony within the home, thus building a stronger support system for the child with a disability.

Definition of Terms

The following key terms will be used throughout this capstone. The definitions below are intended for the reader to understand the key terms within the context of the research question.

- *Acceptance* refers to the psychological and emotional response to a person or situation without expecting change (Bordieri, 2021).
- *Birth order* refers to the chronological order in which children are born and placed into a family (Damian & Roberts, 2015).
- *Caregiving* refers to a person who attends to another person's daily needs (Schulz & Eden, 2016).
- *Coping mechanism* refers to a behaviour that intends to decrease anxiety and/or negative emotion in a stressful situation. The individual can be either consciously or unconsciously aware of behavioural adjustment. The overall purpose is to manage internal and external stressors (American Psychological Association, n.d.-a).
- *Developmental disabilities*, referred to as IDD (intellectual disability) in the *DSM 5-TR*, within neurodevelopmental disorders, is defined as a disorder developed during onset of the developmental period, involving deficits in intellectual functioning and adaptive functioning, resulting in limitations on independence and social responsibility (American Psychiatric Association, 2022). The *ICD-11* refers to the term as disorders of intellectual development, under neurodevelopmental disorders (World Health Organization, 2025). The *ICD-11* defines the term as conditions that are characterized by a reduction in intellectual functioning and adaptive behaviour in the developmental period. It also

distinguishes the disorder on levels of severity such as mild, moderate, and severe (World Health Organization, 2025).

- *Family unit* refers to a structural unit combined of individuals living in a household who provide each other emotional, social, and physical support. Individuals may be related to one another by birth, marriage, or adoption (Health Resources and Services Administration, 2022).
- *Meaning-making* refers to the process that is used to understand and interpret events or experiences that occur. The process includes understanding the experience's significance through interpretation and identifying the feelings that shape the individual's understanding (Zittoun & Brinkmann, 2012).
- *Parenting styles* are how caregivers interact, discipline, and nurture their children. There are different parenting styles such as authoritative, permissive, and authoritarian style (Sanvictores & Mendez, 2022).
- *Resilience* refers to the ability of families and individuals to overcome and face adversity. Contributing factors of resilience include the ability to problem-solve, emotional regulation, support, and stability (American Psychological Association, n.d.-b).

Outline of Chapters

This capstone paper will be comprised of three chapters to answer the following research question: How to families with a child with a developmental disability cope and find meaning of the diagnosis? Chapter one outlined an introduction to the topic and highlighted the purpose statement, theoretical frameworks, methodology used, contribution to the field of psychology, and a positionality statement. A list of key terms and definitions was also provided to make the literature review easier for the reader to follow. Chapter two consists of a comprehensive review

of the literature regarding families who have a child with a developmental disability and how they cope and find acceptance. This review will be divided into various components. Initially, there will be a review of the emotional impact a family experiences upon receiving the diagnosis of a developmental disability, followed by how they find meaning-making and acceptance. The literature review also is organized around how the effect differs between parents and siblings of the child. The shift in family dynamics and role adjustments is examined. Chapter three will discuss the gaps within the literature review. A plan of action will also be shared so that clinicians can apply the research findings within their practice. Concluding the capstone will be a written reflection of the overall learning experience.

Chapter Two: Literature Review

This literature review aims to explore the different factors that shape the family dynamic, their coping mechanisms, and the rate of acceptance of their child who has a developmental disability. Not only will this review synthesize the findings of the family at large, but it will also explore the relationship between the parents, and the impact the diagnosis has on the siblings. Additionally, cultural influences will be explored as well as how this impacts support systems. The importance of this literature review is to understand the significance of not only creating a support system for the child with a disability but also for the child's caregivers. The purpose is to critically analyze the literature to explore the research question of how families cope and find acceptance of having a child diagnosed with a developmental disability.

Understanding Family Experiences of a Developmental Disability Diagnosis

The process for a family to receive a diagnosis of a disability for a child can be a long, complex journey, often representing a pivotal family experience. The diagnostic process is an ongoing journey often met with appraisal, re-appraisal, and further adaptation (McGlinchey et al., 2024; Su et al., 2022). Families of a child with a developmental disability report experiencing a sense of grief and loss with having their worldview changed (Mahat-Shamir & Huri-Rotman, 2024). Along with grief, an array of emotions is opened, such as grief and denial, followed by seeking meaning-making from the diagnosis (E.-J. Lee et al., 2024; Li et al., 2024). For many families, the diagnosis represents a loss of the future they had imagined for their child and walking into an unknown, unfamiliar territory (Gray et al., 2023). The research also highlights how the psychological strain associated with the period of diagnosis is also met with catalyzation of the resiliency and new understandings of the family unit (Malka & Fine, 2024; Park, 2013; Walsh, 2003).

Emotional Impact of Diagnosis

The family not only struggles to deal with grief from receiving the diagnosis but also experience a sense of loss towards the life they expected for their child and grieving their child's future (Mahat-Shamir & Huri-Rotman, 2024). As parents describe their lived experience, they share that not only are they experiencing the emotional impact of the disability, but they are also mourning a sense of normalcy that is expected from raising a neurotypical child (Bakula et al., 2024; Gray et al., 2023). Along with denial, shock, and anger, families also face stigma and judgment. Su et al. (2022) conducted a study in China which indicated societal stigma influences parental stress with their children. The study included qualitative interviews with 34 families who had a child with a developmental disability, using the Family Life Interview. It provided insight into adapted family routines, balancing caregiving demands, and limited services through cross-sectional and urban samples. The studies reliability was enhanced through the use of systematic coding across several researchers and a validated instrument (i.e., the Family Life Interview), which was adapted for Chinese families. Although the research exhibited validity through achieving triangulation within interviews, it also relied on parental self-reports. The study how culture can impact families' perceptions of a person with a disability and how this impacts the parents from facing judgment (Su et al., 2022). This study reinforces the need to provide culturally responsive supports in Canada.

There are often mixed feelings that some families face the moment they receive their child's diagnosis. For instance, research by Bakula et al. (2024) found that some families reported feeling a sense of relief and clarity when being provided an answer about how their child is. The research presented an in-depth, single case-study of a parent who has a child with a feeding disorder that received six sessions of acceptance and commitment therapy (ACT)

through telehealth. The results of the study indicated a reduction in parental stress and improvements in parenting practices. While the findings of this study by Bakula et al. (2024) cannot be generalized because of its small sample size, it provides insights in the emotional experiences of parents who feel a loss of autonomy and control during their child's diagnosis and treatment process. This case highlights the critical role that service providers play in restoring a sense of agency and collaborative decision-making in parents of a child with a disability (Bakula et al., 2024). By providing clear communication and involvement with the families, feelings of disempowerment are mitigated, and there is an increase towards acceptance of their child's diagnosis of a developmental disability.

Meaning-Making and Acceptance

Research shows that families engage in finding acceptance and developing meaning by reinterpreting expectations to work through the challenges that follow receiving a diagnosis (Park, 2013; Walsh, 2016). The theoretical framework by Park (2013), the meaning-making model, holds that distress appears when situational meaning conflicts with global meaning, indicating that families move towards acceptance by reframing the stressor or by modifying their belief systems. Although this concept is widely applied across various trauma and illness contexts, it has its limitations through a lack of empirical testing. The family resilience framework by Walsh (2021) also highlights belief systems, organizational patterns, and communication that enables positive adaptation under the face of adversity. Walsh's framework is influential within family therapy and resilience research as it integrates family systems and ecological perspectives; however, it also requires contextual tailoring to population such as those with developmental disabilities (Walsh, 2021).

Research illustrates how meaning-making is further shaped by culture and context. McGlinchey et al. (2024) interviewed 30 caregivers from the U.K. who identified that caregiver identity, social connections, and health promoting practices were all important to overall parental well-being. The credibility of this study was enhanced as its strengths included involving both the patient and the public in the design. However, the findings were limited due to the sample being relatively homogeneous to the U.K. and may not be generalized across diverse populations (McGlinchey et al., 2024). Similarly, in interviews with 34 Chinese families, adaptation involved prioritizing the child's needs while preserving family harmony through negotiating resources and stigma (Su et al., 2022).

Research also indicates that meaning-making interventions can reduce stress and restore parental agency. For instance, Bakula et al. (2024) reported that parents who have a child with a feeding disorder had significant reductions in stress and overall improvements in family functioning after receiving six sessions of ACT. Although the case study only included a single participant and relied solely on self-report, its strengths include using validated measures of stress and highlighting the feasibility through using telehealth services (Bakula et al., 2024). Meaning-making refers to the family finding a new perspective on their experience of raising a child with a disability in a way that aligns with their worldviews (Bakula et al., 2024). For instance, collectivist cultures find strength and community in having extended family members support in caring for a child or other family members (C. Lee et al., 2022; Su et al., 2022).

ACT views caregivers finding acceptance by aligning personal values with behaviours. Results from a study by Bakula et al. (2024) reported that parents who underwent ACT found a positive shift in accepting their child's diagnosis. Parents reported that they experienced less resistance following the therapeutic intervention and described themselves as working towards

embracing their child. ACT interventions focus on mindfulness and value-based action, which allows caregivers to connect with their child's strengths and capabilities (Bakula et al., 2024).

Culture influences how families understand their child's diagnosis. For instance, families in China reported that having a routine and following rituals supported their stress levels by providing a sense of stability in their daily lives (Su et al., 2022). These actions are commonly seen in collectivist cultures. On the other hand, individualistic cultures advocate for access to resources for inclusion and development for the family's children (Gray et al., 2023). Gray et al. (2023) conducted their study in Australia, examining siblings of children with Down syndrome and Rett syndrome. The study reflects individualism in that emphasis was placed on siblings accessing resources for inclusion and development (Gray et al., 2023). The difference in cultural approaches describes collectivism valuing family unity, whereas individualism values individual autonomy. Therefore, it is important to be mindful of these differences when implementing an approach that supports families in their meaning-making experience.

In collectivist cultures, such as the study conducted in China, families emphasize maintaining harmony and restructuring daily life in order to meet the needs of the child with a developmental disability (Su et al., 2022). In contrast, based on research conducted within individualistic cultures, such as Gray et al.'s (2023) work in Australia, there is an emphasis on advocating for inclusion and resources. For instance, Gray et al. highlighted that although siblings of a child with a developmental disability were compassionate and mature, they lacked parental time, reflecting an individualistic framework. These studies provide insight into how cultural values often shape and influence the balance of collective family adaptation and individual access to resources.

Parental Perspectives

Parents' experiences after they receive the diagnosis of their child's developmental disability has been extensively studied through qualitative and quantitative research. Su et al. (2022) conducted interviews with 34 Chinese families, which resulted in the discovery of parents describing grief, stigma, and uncertainty. The findings also indicated that parents ought to preserve harmony and restructure their routine to create sustainable family living. Similarly, Gray et al. (2023) conducted a survey with 156 parents who had children diagnosed with Down syndrome and 149 parents of children diagnosed with Rett syndrome in Australia. Gray et al. found that parents reported on limited family recreation and reduced time for their neurotypical children, particularly in families with children with Rett syndrome. The reliability of Gray et al.'s study is high due to the large sample size. The case study by Bakula et al. (2024) demonstrates that using meaning-focused interventions, such as ACT, can promote parents' sense of agency and acceptance. The findings from all the studies collectively illustrate that parental perspectives are influenced by cultural norms, family roles, and supportive interventions.

Research indicates that resiliency in parents is built by connecting families and communities who share similar experiences (Gur & Reich, 2023; Malka & Fine, 2024; McGlinchey et al., 2024). McGlinchey et al. (2024) found that peer support networks and opportunities to discuss shared experiences were imperative to caregiver well-being. Moreover, Malka and Fine (2024), using photovoice with 24 Israeli parents, highlighted those higher levels of engagement through community and services supported parents in feeling more empowered as they navigated and engaged through support services for their family. This research design provided insight into the parents lived experiences; however, it has limitations as the

participants' relations were context-specific (Malka & Fine, 2024). The role of connectedness was highlighted in a systemic review by Gur and Reich (2023). Their review of six spiritual based programs provided insight on community and group practices reducing caregiver strain and promoting resiliency (Gur & Reich, 2023). The limitation of Gur and Reich's study is that it is based on limited evidence. Therefore, combining all these findings suggest that social connection, validation, and engagement in the community are important protective factors for parents to feel supported and empowered as they work towards acceptance of their child's developmental disability diagnosis.

Family Dynamics and Role Adjustments

Research indicates that when a family is given a diagnosis of their child having a developmental disability, there is a shift in the family dynamic, an adjustment in the family members' roles, and a change in responsibilities (Dinç et al., 2024; Gray et al., 2023; Mestre et al., 2024; Su et al., 2022). In a systematic review of 10 studies, Mestre et al. (2024) found that a family-centred care approach strengthened the partnership between parents and professionals, enhanced parental empowerment, and improved overall quality of life in the family. Their research design included both quantitative and qualitative research, which provided an overall balanced view of the findings. However, a large portion of studies were conducted in Western countries, limiting representation for families who follow collectivist cultures or reside in low resource contexts (Mestre et al., 2024). Therefore, it is challenging to draw generalizable conclusions based on the findings of using the family-centred care approach with the general population. The change is often influenced by what the child's needs are, how much support is available, and cultural influences and expectations (Mestre et al., 2024). There will be an exploration of how siblings, parents, and marriage are shifted because of caregiving demands

and navigating the emotional impact. By understanding the family dynamic and change in role adjustment, as service providers, we are better able to support the families in navigating their journey of acceptance and meaning-making.

Sibling Perspectives

It is assumed that parents are often the primary caregivers of children with developmental disabilities; however, research indicates that siblings also provide meaningful roles and are impacted by the diagnosis (Dinç et al., 2024; McHale et al., 2015). In a qualitative study of Turkish mothers, Dinç et al. (2024) reported that siblings experience a pressure to be perfect, feeling guilt and shame and taking on a variety of caregiving responsibilities. The study shows how siblings also navigate a complex range of emotions to adjust to the changes within the family unit (Dinç et al., 2024). Although this study is limited to parental perspectives, the findings suggest that siblings experience intensified emotional burden and sibling role strain due to cultural expectations (Dinç et al., 2024). On the other hand, positive outcomes are shown in other studies (Gray et al., 2023; McHale et al., 2015; Woodgate et al., 2016). Woodgate et al. (2016) interviewed Canadian siblings of children with complex care needs and found that the siblings experience both ambivalence and deep attachment when it came to meeting the health daily living demands of their sibling with a disability. This finding indicates that resilience, empathy, and maturity are also met with feelings of frustration and loss (Woodgate et al., 2016). In a theoretical review of sibling literature with families who have a child with ASD, McHale et al. (2015) highlighted sibling's experiences, emphasizing that warmth and closeness are commonly seen in some families whereas others show patterns of conflict and emotional distance. This difference is dependent on factors such as the severity of the disability and how parents treat the child and the siblings. Gray et al. (2023) support these findings; based on their

survey of over 300 Australian parents of children with Down syndrome and Rett syndrome, they reported that the siblings who were described as compassionate and mature also acknowledged that the parents provided them with limited attention and did not engage in as many family activities. These studies highlight that siblings are active participants in the family system as caregivers, with both positive and negative adaptations that shape the families' overall experience in meaning-making and finding acceptance.

Siblings also experience challenges as a result of the diagnosis. Research also indicates that siblings' experiences are shaped by processes of parentification in which they like responsibilities within the family unit. Łada-Maśko et al. (2024) identified parentification as an outcome to be measured in their Polish case-controlled study. They sought to measure parentification through standardized tools such as the Parentification Questionnaire for Youth as well as measuring psychosocial indicators such as internalizing and externalizing behaviors. The findings of their study are still ongoing; however, their research highlights a shift toward capturing how caregiving roles may be transferred on to the siblings (Łada-Maśko et al., 2024). Paul et al. (2021) examined lower- and middle-income regions through qualitative the amount link analysis in which siblings presume care grouping responsibilities more frequently. Their findings show that siblings' parentification is often at the expense of their education and social opportunities, but this has been indicated as the norm collectivist cultures (Paul et al., 2021). Although the study consisted of a smaller sample size, it highlights how cultural norms can simultaneously foster resilience while imposing strains (Paul et al., 2021). C. Lee et al. (2022) conducted a survey of 576 adult siblings across South Korea, Japan, and Taiwan, in which they reported lower levels of preparedness for future caregiving and that gendered expectations, mostly for sisters, created assumptions that the siblings would provide future care. Although this

study was cross-sectional and relied on self-report data, its large sample across nations increases its reliability. Collectively, these studies indicate how siblings' roles extend beyond companionship with their sibling and include caregiving and parentification, which can evoke both a sense of burden and growth (Łada-Maśko et al., 2024; C. Lee et al., 2022; Paul et al., 2021). The lived experiences of siblings are central to the family's adaptation and process towards meaning-making and acceptance as they both navigate empowerment and strain as a response to the diagnosis of a developmental disability.

Parent-Child Interactions

The relationship between the parents and the child also becomes impacted following the diagnosis of a developmental disability. In Jajodia and Roy's (2022) study that investigated experiences of parents who had a child with ASD, parents reported a shift in their parenting style, which incorporated more patience, adaptability, and advocacy. Parents described flexible approaches towards discipline and caregiving, which created stronger bonds despite experiencing high levels of stress. The study used validated attachment and stress measures which strengthened the reliability of the findings. However, the sample was largely maternal caregivers, which limits the generalizability of their conclusions (Jajodia & Roy, 2022). Parents described the role of parenting as an opportunity to grow with their child indicating that they reframed parenting as a process of learning and connecting (Paul et al., 2021). In their multi-regional qualitative study, Paul et al. (2021) found that parents and siblings from diverse cultural settings experienced both the burden and growth that came with caregiving responsibilities, indicating resiliency by redefining family roles. The study was credible because of their use of triangulation of sibling, parent, and expert perspectives despite its small sample (Paul et al., 2021). The longitudinal study by Bahri et al. (2023) showed that the parent-child bond can be both an

indication of closeness and stress. In a 28-year study of 219 U.S. families raising children with developmental disabilities, it was reported that although parents described feeling a deeper sense of empathy and attachment over time, others experienced stress, guilt, and relational strain during their child's early years and adolescence (Bahri et al., 2023). The study indicated strong validity due to its long-term range. These studies show that the parent-child relationship is shaped by cultural context and provided supports, and a balance between the demands of caregiving provides an opportunity for connection between the child and the parent.

Researchers have also found that a child's diagnosis of a developmental disability impacts parenting styles. Jajodia and Roy (2022) found that parents who reported higher levels of stress were associated with harsher or inconsistent discipline reflecting either authoritarian or permissive parenting styles. They also reported that secure attachment was linked to responsive caregiving practices such as authoritative parenting. The findings of this study indicate that the parenting style is not fixed based on a child having disabilities but rather the style varies depending on parental stress and the quality of their relationship (Jajodia & Roy, 2022). Paul et al.'s (2021) study demonstrates that in collectivist cultures, parents have a stricter discipline approach with the siblings in order to preserve family order, indicating an authoritarian style. There were some parents in their study who shared the opposite in that they engaged in authoritative approaches that aligned more with learning and mutual growth; however, the majority indicated authoritarian (Paul et al., 2021). McGlinchey et al. (2024) observed that the identity of parents and promotion of health practices also influenced how parents engaged with their children. They described that many indicated authoritative parenting styles, which fostered patience and empathy in their practices (McGlinchey et al., 2024). All these findings suggest that after receiving a diagnosis, parenting styles reflect both the stress and cultural norms in

caregivers. Using authoritative approaches promotes higher resiliency whereas authoritarian or permissive parenting styles may increase strain and stress.

Marital Dynamics

The relationship between parents is impacted as a result of the caregiving responsibilities of raising a child diagnosed with a developmental disability. There are consistent findings in research that indicate the stress from increased responsibilities, financial pressures, and grief take a toll on marital relationships (Bahri et al., 2023; Molero et al., 2023). In Bahri et al.'s (2023) 28-year longitudinal study, there was a 36% divorce rate by time the child turned 30, with higher risk during their early childhood and adolescence years. Caregiver demands during that period was most intense, and parents reported struggling to balance their relationship and caregiving responsibilities simultaneously. The length of this study is a significant strength; however, a limitation includes the sample being limited to U.S. specific contexts (Bahri et al., 2023). Molero et al. (2023) consulted 197 Spanish parents who had children with intellectual disabilities and found that affiliate stigma (i.e., parents who internalized negative societal attitudes) was strongly correlated with lower marital satisfaction. Reliability was shown in this study through validated stigma and the use of marital quality scales (Molero et al., 2023). The findings from Molero et al. suggest that stigma not only affects the well-being of parents but also creates a strain on marital relationships. Protective factors were self-efficacy and the use of social supports, suggesting that external and internal resources can mitigate the risks of marital strain.

Although the research shows a risk of marital strain and divorce, couples also reported experiencing a sense of strength and bond as they worked together on stressors associated with caregiving (Roth et al., 2022). In a systematic review of 32 studies on dyadic coping across caregiving contexts, Roth et al. (2022) discovered that couples who used collaborative problem-

solving techniques and engaged in emotional support with each other reported higher marital satisfaction, higher levels of resiliency, and an ability to navigate external stress. Indicators of positive dyadic coping included shared responsibility, open communication, and emotional validation. Indicators of negative dyadic coping included qualities of withdrawal, avoidance, and hostility, correlating to increased distress in the relationship (Roth et al., 2022). The study drew on both qualitative and quantitative methods, indicating a rich conceptualisation of dyadic coping. However, a limitation of the study includes limited effect size due to a lack of differences between the samples. Overall, Roth et al. provide valid and reliable findings on dyadic coping and how it plays a crucial role in determining the strength of a marriage in relation to caregiving demands.

Research indicates that the romantic and intimate relationship between parents can often be impacted by caregiving responsibilities and its emotional demand to care for a child with a developmental disability (Doyle & Cicchetti, 2017; Simpson et al., 2017). Doyle and Cicchetti (2017) conducted a qualitative study of Irish couples raising children with disabilities. The researchers found that many parents described experiencing a loss of intimacy, sexual exhaustion, and disconnection because their time and energy was consumed with caregiving tasks. There was an emphasis on exhaustion and different sleep schedules, which presented a barrier towards opportunities for physical connection. A limitation of this study is due to its small sample size impacting generalizability; nonetheless, it provides insight into lived experiences, which are often underrepresented in quantitative surveys (Doyle & Cicchetti, 2017). Simpson and Rholes (2017) examined attachment style between couples caring for children with developmental disabilities. They found that securely attached partners were more likely to engage in co-regulation techniques, collaborative problem solving, and healthy communication,

increasing marital satisfaction. Disparities were found with those who exhibited anxious or avoidant attachment styles, leading to a struggle in communication. Partners who had an anxious style became emotionally reactive whereas avoidant partners exhibited symptoms of withdrawal under stress (Simpson & Rholes, 2017). The study highlights that attachment style can either create a barrier or strengthen the challenges presented from caregiving stress, indicating the importance of couple focused intervention (Doyle & Cicchetti, 2017; Simpson & Rholes, 2017).

Research suggests role diffusion as being another challenge that affects marriage quality (Ribeiro et al., 2021; Zvara et al., 2018). Ribeiro et al. (2021) and Zvara et al. (2018) found that parents reported feeling more like co-caregivers rather than romantic partners, as the responsibilities of caretaking often overshadowed their identity of being a married couple. Reduced intimacy, emotional exhaustion, and relational dissatisfaction were all contributing factors to caregiving roles being interconnected, overtaking marital status (Ribeiro et al., 2021; Zvara et al., 2018). Bahri et al. (2023) also found that parents reported a lack of emotional and physical intimacy with their partner mostly during periods of high stress. Parents also reported their marriage as being more functional than romantic (Bahri et al., 2023). The longitudinal scope of Bahri et al.'s study enhances the reliability of the findings which indicate how stress impacts intimacy and connection across different developmental stages of a child with a disability.

Collectively, the studies suggest that marital dynamics following a child's diagnosis of a developmental disability are varied (Bahri et al., 2023; Doyle & Cicchetti, 2017; Ribeiro et al., 2021; Simpson & Rholes, 2017; Zvara et al., 2018). In one aspect, couples are at risk of experiencing relational strain, a lack of intimacy, and divorce when faced with stress and stigma that overtakes how they cope. In another aspect, healthy dyadic coping and secure attachment

have shown to strengthen marital bonds, promote collaboration, and increase resilience (Bahri et al., 2023; Doyle & Cicchetti, 2017; Ribeiro et al., 2021; Simpson & Rholes, 2017; Zvara et al., 2018). Roth et al. (2022) highlight interventions targeting couples' communication and collaborative coping as a way to reinforce resilience within marital relationships. By incorporating supports such as couples counseling, family-centred care, and psychoeducation on attachment styles, it will support sustaining marital bonds that in turn strengthen the overall family system promoting their journey towards meaning-making and acceptance (Roth et al., 2022).

Coping Mechanisms and Support Systems

Empirical studies indicate that families who have a child with a developmental disability engage in a mixture of coping strategies and support systems to work through the social and emotional demands met after diagnosis (Gur & Reich, 2023; McGlinchey et al., 2024; Su et al., 2022). Some families have reported using strategies such as creating predictable routines and engaging in problem solving, utilizing peer and community service networks, drawing upon spiritual or cultural belief systems, and engaging in structured skill-based therapies such as ACT (Bakula et al., 2024; Gur & Reich, 2023; Malka & Fine, 2024; McGlinchey et al., 2024; Sutherland et al., 2024). The strategies across all these studies have been associated with decrease levels of caregivers' stress, increased resilience, and overall improved family functioning (Gur & Reich, 2023; McGlinchey et al., 2024; Sutherland et al., 2024). Not all these studies can be generalized due to the variety of samples used; therefore, researchers frame these linkages as associations with one another, meaning what counts as adaptive is dependent on the context (McGlinchey et al., 2024; Su et al., 2022). This limitation is due to most of the studies being qualitative, small scale, and/or cross-sectional (McGlinchey et al., 2024; Su et al., 2022).

Applying cultural sensitivity should be used within service contexts when adapting coping strategies.

Adaptive Coping Strategies and Resiliency

Adapting coping strategies provide an essential role in the way families respond to immediate and future stressors that may arise from raising a child with a developmental disability. The literature identifies one coping strategy as connecting to spirituality (Gur & Reich, 2023). In a systematic review of six spiritual based interventions, Gur and Reich (2023) found that parents and caregivers who engaged in mindfulness and gratitude reported lower levels of stress and higher resiliency. A strength of their research indicates that a cross-cultural scope was provided, and protective factors were emphasized that promote acceptance. A limitation of the study is its small number of studies and limited methodological diversity, limiting the generalizability of their findings (Gur & Reich, 2023). Sutherland et al. (2024) also identified incorporating structure into family routines as an adaptive coping strategy. In a trial of a family-centred connections program, the researchers found that establishing routine reduced stress within caregivers, aligning with the ecocultural framework. This finding suggests an emphasis on daily structure promotes long-term resiliency (Sutherland et al., 2024). Although a limitation of the study by Sutherland et al. was its reliance on self-reports and small sample sizes, its reliability was strengthened due to its use of validated stress measures. Altogether, these findings highlight that incorporating spirituality and daily structured routines enhance adaptive coping strategies and promote resilience (Gur & Reich, 2023; Sutherland et al., 2024). These coping strategies and enhanced resilience enable families to maintain the demands of caregiving while also working towards the concept of acceptance of their child's diagnosis of a developmental disability.

Therapeutic approaches such as ACT have also been shown to increase resiliency in parents of children with developmental disabilities (Bakula et al., 2024). Bakula et al. (2024) designed a single-case intervention with a parent who had a child with a disability. The parent participated in six ACT sessions and reported reductions in caregiver burnout and emotional exhaustion, as well as better alignment with their parenting practices and personal values. The study highlights that ACT overall promotes adaptive coping strategies by parents staying grounded in their values rather than experiencing overwhelming distress (Bakula et al., 2024). The validity of the study was enhanced by using standardized testing for burnout and stress, but the researchers relied on a single participant, which limits the generalizability of their findings (Bakula et al., 2024). However, Bakula et al.'s study still suggests that parents engaging in ACT reduces levels of stress by integrating their coping strategies with their personal values and caregiving approaches.

Gendered Experiences of Coping

Gender roles and societal expectations often impact caregiving responses and the way individuals process emotions. Li et al. (2024) conducted a cross-sectional survey of 200 Chinese parents who had children diagnosed with ASD. Their findings indicate gender differences in stressors. For instance, mothers reported higher levels of stress and emotional burden as they were more likely to take on primary caregiving responsibilities. Fathers, on the other hand, leaned on problem-solving tendencies and reported financial stressors and feelings of helplessness (Li et al., 2024). Li et al.'s study was reliable because it had a large sample and used validated scales to measure stress and coping, but they were limited to assessing a single cultural context, so their findings are not generalizable to other cultural contexts. Although the results

should be extended to other populations with caution, the findings still suggest that gender-based expectations influence how parents experience stress.

Gray et al. (2023) distributed a survey to 322 Australian parents raising children diagnosed with Down syndrome or Rett syndrome. Their findings showed that mothers were more likely to seek out support networks, such as attending parent groups, therapy, or engaging in conversations with friends and family, to navigate their emotions and express their feelings. In contrast, fathers were reluctant to reach out to their community network for support as a result of cultural norms around masculinity and masking emotional expression (Gray et al., 2023). Fathers focused on task-oriented coping strategies, such as daily problem solving or managing finances, while mothers sought out social networks to manage their emotional stress (Gray et al., 2023). Although the gender differences in the study are an important finding on the different ways parents cope individually, Gray et al. (2023) emphasize that not all parents take on these roles or conform to cultural expectations around masculinity and caregiving responsibilities. A limitation of the study indicates there is a risk of over generalizing the findings to all mothers or to all fathers (Gray et al., 2023).

Gender role strain has been found to be a contributor to caregiver burnout and resentment. McGlinchey et al. (2024) conducted a qualitative observation of parent caretakers in the United Kingdom and identified that mothers felt a lack of recognition and support from their partners and extended family members for taking on more caregiving responsibilities. The imbalance led to feelings of resentment, emotional exhaustion, and burnout (McGlinchey et al., 2024). This qualitative research design provided in-depth insights but is weaker in its external validity due to its small sample size (McGlinchey et al., 2024). The study highlights the importance of acknowledging the unbalanced caregiving rules that contribute to tension within

families (McGlinchey et al., 2024). Practitioners can work on fostering healthy relationships in family dynamics by recognizing and validating the different approaches that parents take to cope.

Cultural Influences

Research indicates that cultural context plays a role in shaping how families respond to the challenges of having a child with a developmental disability. In a study conducted by C. Lee et al. (2022), a survey of 576 adult siblings of individuals with intellectual and developmental disabilities across South Korea, Japan, and Taiwan indicated that siblings were expected to take on long-term caretaking roles. The findings reflect how shared responsibility is common in collectivist cultures. Additionally, in collectivist societies, caregiving responsibilities are shared amongst extended family members and social networks, reducing individual stress. However, using a communal approach can also create tension between family members regarding child-rearing decisions (C. Lee et al., 2022). Although the results indicate strong validity due to its larger sample size, caution should be placed on extending these findings towards all other collectivist cultures across the globe. Overall, C. Lee et al.'s research shows that communal caregiving may result as a protective factor and can become a source of conflict within the family structure.

Families in individualistic cultures engage in a family structure where parents are the primary caregivers. McGlinchey et al. (2024) conducted a survey of parent caretakers based in the U.K., and their findings suggest that having a sense of autonomy in decision-making around self-care and navigating services are priority for sustaining overall family well-being. The findings further highlight that in individualistic cultures, not having extended family involved increases parental stress but also promotes advocacy skills and autonomy (McGlinchey et al., 2024). In another study, Bakula et al. (2024) found that parents reported benefits from aligning

their personal values with their caregiving practices. The results highlight the importance of using individualized coping strategies in Western countries (Bakula et al., 2024). In a qualitative study of Irish couples conducted by Doyle and Cicchetti (2017), results indicated lower levels of intimacy and higher relational strain in nuclear families due to parents lacking support from extended family members. However, couples in this study reported a greater sense of autonomy in their decision-making process (Doyle & Cicchetti, 2017). Overall, these studies demonstrate individualistic caregiving promotes resiliency through the use of autonomy, advocacy, and engaging in individualized coping strategies, although it places responsibility predominantly on the parents.

Navigating Support Systems

Families' adaptation to the challenges of raising a child with a developmental disability is significantly shaped by their access to formal and informal support systems. Research indicates that families who were able to engage with healthcare, education, and advocacy networks reported lower stress and a strong sense of autonomy and empowerment in their role as caregivers (Burton et al., 2017; Sutherland et al., 2024; Woodgate et al., 2016).

Burton et al. (2017) evaluated an intervention program known as the Nurturing Program, which is designed to provide strategies and tools for parents of a child with a developmental disability. Their evaluation found that parents reported improvements in coping, increased levels of confidence as a caretaker and to manage challenges, as well as increased ability to access community resources (Burton et al., 2017). The study measured pre- and post-outcomes in its design thereby increasing its validity, but it relies on self-report with limited follow-up data; as such, there is uncertainty in the long-term effectiveness of the program. Overall, Burton et al.'s

study highlights the importance of using targeted parenting programs to strengthen resilience and navigate through systems.

Another component that functions as part of a family support network includes the school where children spend a significant portion of their lives. Woodgate et al. (2016) conducted a qualitative study of Canadian families raising children with complex care needs. They found that inclusive school environments provided tailored learning opportunities for children as well as emotional and social support for the parents who were able to connect with other families who had shared experiences. A limitation of the study includes its small sample size and the focus on the Canadian healthcare and education systems, which limits global generalizability. The focus on Canadian systems provides direct insight into how Canadian counsellors can integrate this information in their practice. Additionally, these findings are from 2016; therefore, results should be interpreted with caution in 2025 post pandemic (Woodgate et al., 2016). In another Canadian survey of parents conducted by Udhmani et al. (2023), results showed persistent challenges such as long waitlists for specialized services, a lack of inadequate funding for inclusive programs, and the emotional burden of having to advocate for their child's educational needs. A strength of this study comes from its overview of national scope and contemporary data; however, it is limited because it relies on self-reports (Udhmani et al., 2023).

Informal peer-based support services play a crucial role in how families adapt to a child with a developmental disability. Sutherland et al. (2024) studied how family connection programs support family adaptation. Results indicated that participation in peer support groups provided parents with emotional validation, reduced feelings of isolation, and provided access to up-to-date resources. The study is subject to self-selection bias because the families who sought out support groups may already experience a higher degree of motivation to engage with

resources (Sutherland et al., 2024). Despite this limitation, the evidence still suggests that community-based support programs enhance resilience by normalizing caregivers' experiences and their abilities to navigate formal systems.

Barriers to Accessing Support

Families may seek community and organizational support to access help for their child with a developmental disability. However, research shows that families face systemic and logistical barriers that limit their access to effective and timely support, which can discourage them in asking for assistance with their child and family (Sutherland et al., 2024; Udhmani et al., 2023).

Structural and Institutional Barriers

A common challenge that families report is impatience and frustration with long wait times for receiving assessments, access to therapeutic services, and educational support. In a national Canadian survey of parents, Udhmani et al. (2023) found that families frequently described waiting between 1–2 years for developmental assessments in the public system, while private assessments could still take up to a year. There was increased parental stress associated with these significant wait times and was perceived as impacting the child's developmental progress. A strength of the study is that it involves a national scope and has contemporary relevance; however, its reliance on self-report and unequal provincial participation contributes to its limitations (Udhmani et al., 2023). Sutherland et al. (2024) evaluated Canadian family support programs. The researchers identified that after receiving a diagnosis, families were placed on additional waitlists for therapeutic interventions such as speech and language therapy, occupational therapy, and applied behavioral analysis interventions (Sutherland et al., 2024). Although these findings highlight systemic barriers, wait times vary province to province,

service type, and funding model, so the findings cannot be generalized towards all families in Canada.

Fragmented service coordination is also reported as a structural and institutional barrier to accessing services. This disconnect happens when there is a failure in service providers collaborating effectively, resulting in inconsistent recommendations and support plans. For instance, families in Ontario described receiving conflicting intervention strategies between school-based support staff and their child's healthcare providers, leading to confusion and a lack of continuity in care (Udhmani et al., 2023). Families in Alberta, in contrast, emphasized longer wait times but also reported that fragmented coordination was varied based on regional discrepancies in the available specialists (Sutherland et al., 2024). The findings indicate that institutional barriers are not uniform across Canada but rather reflect the decentralized nature of healthcare and education delivery across the provinces. These findings of these studies indicate direct engagement and involvement with families and integrating caregivers' perspectives; however, limitations include the absence of standardized definitions of what fragmentation is as well as a lack of longitudinal data to track how these systemic barriers have evolved over time (Sutherland et al., 2024; Udhmani et al., 2023).

Structural barriers such as long wait times and fragmented coordination contribute to increased levels of parental stress and reinforce feelings of isolation and being unsupported with their child who has a developmental disability. The institutional obstacles also contribute to delaying access to interventions, which can impact a child's developmental trajectory and a family's capacity to adapt to the diagnosis. Addressing these barriers common to coordinated service planning, increasing funding for timely assessments and interventions, and prioritizing family-centred care policies are needed for better coordination in service planning.

Financial Constraints

Financial strain is a challenge for families who are raising a child with developmental disability due to the cost of therapy, specialized equipment, dietary modifications, educational supports, and respite care, all of which tend to exceed what is covered by the government funding system. The Canadian healthcare system provides some access to publicly funded programs, but families often report that these public programs are either underfunded or have limited capacity, requiring them to seek private services at a higher cost (Udhnani et al., 2023).

In a U.S. study, Namkung et al. (2020) surveyed more than 13,000 parents of children with developmental disabilities. Their findings showed that families acquired higher out-of-pocket expenses compared to families without children with disabilities. Parents further reported making financial sacrifices in other areas of their lives such as housing, savings, and leisure activities in order to prioritize their child's needs. A strength of this study includes its large and nationally representative sample as well as usage of validated measures of financial hardship, which also enhances the study's reliability (Namkung et al., 2020). However, since this study was conducted in the United States, there is a difference in the healthcare system and social policies compared to Canada, limiting its generalizability.

Woodgate et al. (2016) interviewed Canadian families raising children with complex care needs and reported similar patterns of financial strain in which parents felt overwhelmed by the cost of equipment, transportation, and home adaptations. Their qualitative design provided a rich description of the families' lived experiences despite its small regional sample size (Woodgate et al., 2016). Udhnani et al. (2023) further expanded the research on how financial stress compounded in immigrant and low-income families who did not qualify for government funded programs or who could not afford private services. These findings indicate how socioeconomic

status acts as barrier and intersects with financial stress and feelings of inequality in society (Udhnani et al., 2023).

Cultural Mismatches

Families from culturally diverse backgrounds often face barriers in accessing support related to language, values, and an understanding of developmental disability. Research shows that immigrant and minority families often encounter challenges such as language barriers, a lack of familiarity with services, and cultural stigma that shape their unwillingness or ability to seek further support for their child with a developmental disability (C. Lee et al., 2022; Su et al., 2022; Udhnani et al., 2023). In a cross-national survey of 576 adult siblings of individuals with intellectual and developmental disabilities located in South Korea, Japan, and Taiwan, C. Lee et al. (2022) found that cultural stigma around disability framed how families interpreted diagnosis and how they accessed services. It was further reported that stigma and a fear of judgement discouraged families from interacting with professionals, while cultural norms about fulfilling family duty reinforced expectations that the siblings would presume the caregiving rules. The strengths of this study include its large sample size and multicultural perspective, but its reliance on self-report and a lack of longitudinal data limits its generalizability (C. Lee et al., 2022). Overall, the findings suggest that stigma and cultural expectations heavily influence families' decision-making and support-seeking for their child with a developmental disability. Su et al. (2022) share that in communal caregiving, otherwise known as co-sleeping, is considered inappropriate in Western cultures but perceived as the norm in collectivist cultures. Having a disconnect between practitioners and families can lead to feelings of mistrust and discouragement from engaging in support services.

Advocacy Burnout

Malka and Fine (2024) highlight the concept of advocacy burnout, which refers to families experiencing emotional and mental exhaustion that arises from battling for adequate access to support services. What contributes to advocacy burnout is filling out many forms for applications and assessments, attending many meetings with different practitioners, and navigating support systems to check for eligibility. It is especially difficult on single parents or those with limited experience or education on how to navigate advocacy. The strength of the study was its attention towards the lived experiences of parents with children who have disabilities; however, the sample size was limited to small urban-based areas, reducing the generalizability of the findings (Malka & Fine, 2024). The findings still highlight a consistent theme in which advocacy provides an additional burden especially when systems are fragmented or underfunded.

Advocacy burnout is seen more commonly among single parents, families with limited education or resources, as well as immigrant households who are unfamiliar with the structure of health and education systems. This level of intersectionality magnifies stress due to the systemic barriers parents must face and the cultural and socioeconomic challenges that impact their ability to advocate effectively (Malka & Fine, 2024; Udhmani et al., 2023). The findings illustrate how advocacy burnout complicates a family's meaning-making process. The families are unable to focus only on the emotional aspect of their child's diagnosis of a developmental disability because parents must allocate their energy towards navigating external systems which can cause a disruption in their process of adaptation and resiliency (Malka & Fine, 2024; Udhmani et al., 2023).

Future Planning and Long-Term Considerations

When families receive news of their child having a developmental disability, they experience a significant amount of anxiety and stress around the future. Research indicates that parents often worry about securing stable caregiving arrangements, financial stability, and awareness of their child's legal rights in order to ensure continuity of care and support throughout their lifespan (Bahri et al., 2023; McGlinchey et al., 2024). The perspective from siblings reinforces these concerns. In a cross-national survey of siblings from South Korea, Japan, and Taiwan, C. Lee et al. (2022) found that siblings would anticipate taking on primary caregiving roles in their adulthood, which would contribute to feeling both stress and resilience in family adaptation. Paul et al. (2021) conducted a multi-regional qualitative study in which siblings reported feeling worried about long-term planning, especially in areas where social services were underfunded or inconsistent. Although these studies differed in their cultural context, they still highlight that future planning is a universal theme that affects families' adaptation processes. It is important for families to work together on preparing for their future and their child's future. This preparation includes ensuring their child's caregiving needs are met, they are financially stable, and they are aware of their legal rights.

Caregiving in Adulthood

The siblings of a child with a disability take on the role as a caregiver in their brother or sister's long-term care team (C. Lee et al., 2022; Paul et al., 2021). Cultural values and family dynamics play significant roles in siblings taking over as the child's sole caretaker as the parents get older. For instance, in collectivist cultures, caregiving is a shared responsibility between members of the family, whereas individualistic cultures emphasize caregiving as a personal choice (Łada-Maško et al., 2024; C. Lee et al., 2022). In C. Lee et al.'s (2022) study of siblings,

it was reported that the expectation is put on the siblings to step in when their parents can no longer take care of the child with a disability. Although this approach provides the parents with a sense of relief in knowing their child will be taken care of, it can also create some feelings of animosity or resentment among the siblings who may not agree with this expectation being put on them. The siblings may feel unprepared or unsupported in taking on this responsibility.

Supporting the siblings by providing them with the knowledge and resources to be their sibling's caretaker is important in getting them ready for success in order to achieve their role effectively. In their mixed methods study of Polish siblings of individuals with intellectual disabilities, Łada-Maško et al. (2024) found that siblings who engaged in caretaking activities at a younger age alongside their parents developed the skills to take on long-term responsibilities. The researchers also found that these siblings developed higher emotional resilience (Łada-Maško et al., 2024). A strength of this study was its use of both standardized resilience skills and qualitative interviews to measure outcomes and lived experiences, increasing its validity of the findings. However, the findings may be only relevant for siblings who grow up in Polish family systems. Their results overall still highlight the importance of parental communication and intentional preparation while also acknowledging how siblings may feel burdened by their responsibility leading to feelings of anxiety.

In individualistic cultures, the siblings who act as caregivers do this by personal choice; siblings voluntarily take on the responsibility of caring for their brother or sister with a disability because of their values. In Paul et al.'s (2021) multi-regional qualitative study on adult siblings in Western countries, siblings who voluntarily took on caregiving roles described this act as being rooted in personal values and relational bonds rather than societal expectations. Although this action was considered solely by the siblings without pressure from the parents, there was a

greater need to establish a formal support system for the siblings to lean on in order to reduce future stressors (Paul et al., 2021). Introducing the siblings to support groups that are specific for them can help them transition into a caregiving role. Furthermore, the findings indicate that when caretaking is voluntary, siblings still require external supports to sustain resiliency and reduce long-term burnout.

Financial and Legal Planning

As part of future planning for families who have children with developmental disability, ensuring the family is equipped financially and legally for the child's future is a crucial component to ensure success in providing and accessing life-long supports (Namkung et al., 2020). Finances are often a barrier that parents face when taking care of their child because of the child's medical needs, education, and additional therapies they must engage in. Namkung et al. (2020) state that creating a long-term financial plan is helpful as it provides comfort for the parents knowing that their child's needs will be met even after they are unable to provide care.

Individuals with a developmental disability may age physically but be cognitively stagnant. Ongoing lifetime cognitive, social, and caretaking support is necessary for these individuals (C. Lee et al., 2022; Paul et al., 2021). As Namkung et al. (2020) suggest, as part of long-term planning, parents should rearrange their child's guardianship and beneficiary to a trusted person. This planning will ease the parent's worries for their child in the future and create a sense of safety and security. Parents can reach out to banking institutions to create a personalized banking profile for the individual with a disability, and they can get in touch with social workers in different government agencies that are tailored for families of children with a disability. By seeking out these supports as part of early intervention, families can reduce their stress levels and create a sense of empowerment to feel like they have control over making

decisions around their child's future. Not only do families construct meaning and acceptance of their child's diagnosis of a developmental disability through emotional adaptation, but they also do so through the development of long-term strategies that ensure their child's well-being. The research findings reflect that acceptance is also indicated through tangible planning and preparedness to ease worry in parents, reflecting a form of resiliency.

Intergenerational Impacts

Caregiving practices and techniques are transmitted through the generations based on learned behaviours and experiences. Once parents age, the children often take over as caregivers to the elders, which also translate to the siblings becoming the caregivers of individuals with a developmental disability (C. Lee et al., 2022). Research indicates that transitions are more successful when families engage in open communication and develop clear long-term caregiving plans (C. Lee et al., 2022; Paul et al., 2021). A study conducted by Bahri et al. (2023) found that transitioning between caregivers with ease was done with a clear and defined plan. Preparation plays a crucial role in reducing caregiver stress.

A study by C. Lee et al. (2022) indicate that intergenerational practices are more common in collectivist cultures because they value strength in family bonds. In their study of siblings across South Korea, Japan, and Taiwan, the participants described prioritizing the caregiving responsibilities for their siblings with a disability over their own career aspirations and life goals (C. Lee et al., 2022). There is also an emphasis in collectivist cultures for following generations to partake in caregiving practices over their dreams and aspirations. Individualistic cultures focus more on communal caregiving practices, which has the benefit of reducing family conflict, but there can be a disconnect among extended family members (C. Lee et al., 2022). Supporting the

families in engaging in group programs or family counselling can help create an open dialogue and create a balance between individual needs and collective responsibilities.

Psychological and Social Impacts

There are psychological and social challenges that can impact families who are raising a child with a developmental disability. A study by Molero et al. (2023) indicate that these challenges include burnout stress and are often caused by receiving stigma and feeling isolated. Stress and burnout can impact how caregivers' parent their children. These stressors can influence the family dynamics and their mental well-being (Molero et al., 2023).

Psychological Well-Being

Research by Dattilo et al. (2024) found that the parents and siblings of a child with a developmental disability were more prone to having their mental health impacted by caregiving responsibilities. The researchers conducted a U.S.-based mixed method study of parents who had children with intellectual and developmental disabilities. Parents reported higher levels of stress, anxiety, and depression compared to parents who did not have a child with additional needs. This study was high in validity due to its usage of standardized methods of mental health and qualitative interviews (Dattilo et al., 2024). There were many emotional and physical demands of caring for their child, and parents reported increased feelings of stress, anxiety, and depression. Chronic stress leads to significant burnout, which implicates the family's ability to cope and adapt to their lifestyle. Furthermore, parents may also feel inadequate in their ability as a provider due to obtaining limited resources or support. Parents undergo burnout cycles, which are best described as moments in which caregivers have a burst of energy and feel hopeful, followed by emotional and physical exhaustion (Dattilo et al., 2024).

Parents can work on reducing the cycle of burnout by accessing specialized services and interventions catered to their individualized care needs. For instance, caregivers can obtain respite care to ensure they are taking time for themselves, and they can attend stress management workshops (Bakula et al., 2024). By accessing a variety of supports, not only for the child but for the families, parents can work on fostering their resilience over time, reducing burnout.

In their cross-sectional study on siblings of children with disabilities in Turkey, research by Dinç et al. (2024) shows that mental health concerns are also present in the siblings as they are also competing for their parent's time and attention, as well as feeling pressure in the family. Ambiguity often arises in the siblings as there is a mixture of feelings of pride and resentment towards their brother or sister. These feelings are common for siblings to experience as the family dynamic changes and the centre of attention is geared more towards the child with a disability, leaving minimal room for the sibling to develop their own sense of identity and belonging (Dinç et al., 2024). Parents can support their other children by working on balancing their caregiving roles and getting the siblings connected to their own peer support groups so they can share with others who may be experiencing similar feelings (Jajodia & Roy, 2022).

The studies illustrate how psychological well-being is an outcome of caring for a child with a developmentally disability, and it is an essential part of how families construct meaning and move towards acceptance. Dattilo et al.'s (2024) research demonstrates the impact on well-being by showing that cycles of burnout inhibit a family's ability to cope, but families that are able to name and recognize these cycles may reframe their stressors as part of family adaptation and developing awareness. Bakula et al. (2024) also address well-being through targeted intervention such as ACT, which allows parents to align their caregiving practices with their personal values, creating a direct link to psychological flexibility and leading to greater resilience

and acceptance of the diagnosis. Jajodia and Roy (2022) highlight that sibling peer support networks encourage positive identity development, which help siblings contextualize their experiences thus supporting them on an individual and family level towards acceptance.

Social Isolation and Stigma

Findings from Molero et al. (2023) show that families tend to feel isolated in their experience of having a child with a developmental disability. Caregivers said they experienced a sense of judgment from others, which led them to feel excluded. For instance, families tended to decline or avoid certain social settings or activities that may have been difficult for their child to partake in (Molero et al., 2023). Not only is this form of isolation detrimental to the family, but it also negatively affects the child who is missing out on an opportunity to gain social skills (E.-J. Lee et al., 2024).

Molero et al. (2023) conducted a quantitative study of 240 Spanish parents. The study reviewed affiliate stigma, otherwise known as the internalization of negative societal attitudes towards disability. The findings indicated that affiliate stigma was associated with increased parental stress, lower marital satisfaction, and a decrease in mental health. There are various forms of stigma that families experience as a result of having a child with a developmental disability. Stigma often emerges in society but then becomes internalized, leading to families feeling shame and blaming themselves for their circumstances (Molero et al., 2023). Expanding on the stigma framework, E.-J. Lee et al. (2024) conducted a mixed-method study on siblings and parents in East Asia and their experience of courtesy stigma, which is when individuals associated with a person with disability face exclusion and judgment on themselves. They found that courtesy stigma was more commonly seen in schools and experienced by the sibling whose brother or sister had a developmental disability. As a result of courtesy stigma, the sibling was

more likely to experience feelings of anger and resentment towards their brother or sister (E.-J. Lee et al., 2024).

Stigma can also present itself in society through inaccessibility to public spaces or having limited inclusivity amongst community-based programs, further reinforcing isolation between families, children, and society (Dattilo et al., 2024). The findings in Dattilo et al.'s (2024) study suggest that society can do its part in creating more inclusive spaces by normalizing disabilities. Through lived experiences, families can advocate not only for their child but also for the community their child is a part of in order to reduce societal stigma and barriers.

Growth and Family Strengthening

Part of human nature is adaptability and resiliency. Although the initial news of the diagnosis may throw the families off balance, they find strength through the challenges they face. In studies by Gray et al. (2023) and McGlinchey et al. (2024), parents reported that the caregiving challenges helped them grow and change their perspective on living. Families who had a child with a developmental disability also felt that they became more empathic towards individuals who presented as different, and they re-defined what success means. Shifting away from being reactive to being proactive guided the families to find meaning and purpose in their situation (Gray et al., 2023; McGlinchey et al., 2024).

Research shows that building a sense of confidence and empowerment is often conducted through partaking in community-based workshops and programs. Families may feel more competent in their abilities to care for their child who has a developmental disability by attending skill-building workshops and joining peer mentorship programs (Burton et al., 2017). By expanding themselves through these networks, families can combat the feeling of isolation and stigma as they are now diving into a community where they feel understood and heard. Research

by Burton et al. (2017) suggests that parents who are involved in specialized programs experience positive associations with advocating for their family and child's needs. Coping with others through shared experiences fosters resiliency and reinforces a sense of connection and support (Udhnani et al., 2023).

In summary, the literature emphasizes that a family's journey with a child's developmental disability is marked by emotional, relational, cultural, and systemic complexities. Across studies, there is a reoccurring theme that families experience grief, stigma, and stress; however, they reframe these challenges into resilience and meaning-making using adaptive coping strategies, cultural practices, and support networks (Bakula et al., 2024; McGlinchey et al., 2024; Su et al., 2022). The family system is reshaped by the diagnosis as parents, siblings, and couples negotiate an interconnected process of adjustment. Methodological strengths in the literature come from the diversity of qualitative studies capturing rich lived experiences, as well as large scale surveys and longitudinal studies that offer generalizable insights (Bahri et al., 2023; Namkung et al., 2020). However, some limitations include a reliance on self-report measures, small sample sizes, and culturally specific constraints in which findings cannot be applied universally (Gray et al., 2023; Li et al., 2024).

Although there are limitations, the literature still demonstrates that resilience and acceptance are not static outcomes but rather an ongoing process that is shaped by psychological well-being, family dynamics, cultural context, and access to support systems. These studies indicate that acceptance is fostered when families are empowered with culturally sensitive supports, strength in relational bonds, as well as opportunities for advocacy and community connections. These findings suggest that meaning-making and acceptance emerge as emotional adaptations and through the use of practices such as future planning, engagement with peer

networks, and the fostering of resilience within the family unit. Overall, the literature indicates that acceptance is a dynamic and relational process that evolves over time, generations, and sociocultural contexts

Chapter Three: Discussion and Applied Practices

The previous chapters explored how families cope with and accept their child's diagnosis of a developmental disability. Chapter one provided an overview of the topic and its relevance for the field of psychology. Chapter two was a comprehensive review of the literature, identifying themes such as emotional responses, meaning-making processes, and role shifts in family systems. This chapter will integrate the findings from the literature review and respond to the research question: How do families of children with a developmental disability cope and find acceptance with their diagnosis? The themes in chapter two will be analyzed in relation to existing frameworks and gaps within the literature. The discussion aims to develop a deeper understanding of the journey families navigate through a life-altering diagnosis and how they make meaning of this experience.

This chapter will begin by summarizing the purpose and providing a reflective synthesis of the material acquired from the literature. Strengths and limitations from the existing literature will be highlighted, in particular, receiving support for siblings and culturally responsive care, and barriers such as stigma, underfunded services, and burnout. A critical analysis will be included regarding how cultural and structural factors intersect with family dynamics and emotional adaptation, emphasizing which areas of support are inadequate or inaccessible.

The chapter will conclude with a discussion of applied practices that will provide a suggested intervention strategy grounded in the research findings. The family resilience and meaning-making support framework will be introduced as a model to support practitioners in helping families move through emotional and relational challenges following the diagnosis of a developmental disability. This framework is based on existing models and theories that are

tailored to the applications and themes within this capstone review. The purpose is to provide real-world techniques for clinicians, teachers, caregivers, and support workers.

Discussion

This capstone explored how families who have a child with a developmental disability cope and find acceptance with their child's diagnosis. Current research was gathered and synthesized to answer the research question. By analyzing and understanding how family members make meaning of the diagnosis, practitioners can develop insights into how they can incorporate how to provide support to this population into their practice. The findings emphasize that a family's journey towards the process of acceptance is multifaceted and evolves over time.

A family's experience with navigating having a child with a developmental disability is filled with complexities that are shaped by emotional, relational, and structural dynamics as depicted through the literature review. Families must adapt their daily structure and worldview based on their child's unique needs. The findings from the literature review show that receiving a diagnosis of a developmental disability evokes feelings of grief, uncertainty, and emotional distress, especially when families perceive a lack of support and face stigma (Mahat-Shamir & Huri-Rotman, 2024; Sue et al., 2022).

The literature highlighted key insights, which is central to the acceptance process for families who have a child with a developmental disability. Meaning-making and resilience were shown to be protective factors, supporting families in adapting to the challenges of receiving a lifelong diagnosis (Gray et al., 2023; McGlinchey et al., 2024). Families who experience the most emotional growth and adaptive coping strategies are the ones who engage in reflective practices such as practicing spirituality, connection through the community, or the use of therapeutic practices (Gray et al., 2023; McGlinchey et al., 2024). Combined, the strategies

provide families with a direction to form meaning, sustain hope, and build on resilience to work through stressors (Gray et al., 2023; McGlinchey et al., 2024). Research from Bakula et al. (2024) indicated that the use of ACT offers tools that align parental values with caregiving behaviours that support emotional regulation and reduce burnout. Additionally, families who engage in a structured routine and maintain a predictable schedule have lower stress levels, especially when they are still in alignment with honouring their family's identity and cultural values (Sutherland et al., 2024).

There are gaps in the systemic supports as indicated in the research. The most significant limitation noted is the inattentiveness towards siblings and extended family members of a child with developmental disability. Siblings and extended family members are also often impacted by the diagnosis; however, they are not always considered during interventions (Dinç et al., 2024; Łada-Maško et al., 2024). Studies identify the emotional burden placed on siblings because of having a sibling with a developmental disability, such as parentification, resentment, or identity struggles (Dinç et al., 2024; Łada-Maško et al., 2024). On the other hand, there is a lack of structured models or resources targeted towards this population, causing a ripple effect in the family dynamics. This challenge is most apparent in family structures that are rooted in cultures which incorporate shared or intergenerational caregiving roles (C. Lee et al., 2022).

Inconsistency in receiving culturally responsive care is also showcased as a gap in the literature and a critical concern. Although collectivist cultures rely on extended kinship, there is also a cultural stigma around disability which prevents families from seeking help from their support system (Su et al., 2022). Alternatively, families in individualistic cultures experience isolation as a result of non-shared caregiving responsibilities and increased pressure for independence (Gray et al., 2023). Families are less likely to engage in supports and interventions

that do not incorporate or acknowledge their cultural values or if they have experienced internalized stigma, leading to reduced mental health outcomes (Molero et al., 2023).

There are structural inequities that further maintain systemic barriers which prevent families from accessing appropriate supports for their child with a developmental disability. Research by Udhmani et al. (2023) discussed how underfunded school systems, lack of government resources, and long waitlists for services significantly affect how families navigate working with a new diagnosis. The research had limited discussions regarding socioeconomic status and its intersectionality with caregiving capacity. Namkung et al. (2020) briefly discussed familial strain on socioeconomic status hindering resilience building through employment instability and financial constraints.

Existing research strongly captures nuclear families' experiences with having a child with a developmental disability (Dattilo et al., 2024; Molero et al., 2023). There is a gap in research exhibiting a multigenerational and intersectional lens and how that captures the emotional aspect of how parents cope with receiving their child's diagnosis. There is limited research conducted on how different family types navigate meaning-making and resilience, such as LGBTQ2S+ families, immigrant families, blended families, and families who have non-traditional caregiving structures. Research by Bahri et al. (2023) noted the emphasis on nuclear family structures influencing intervention approaches as focusing on a deficit in the child and family. This way of thinking develops into a societal structure that views disability as a burden instead of a part of identity and an opportunity for growth (Bahri et al., 2023).

Although the literature highlighted a few limitations, it also depicts a strong capacity for growth, adaptability, and strength through relations in families as they navigate their child's developmental disability diagnosis. Families have reported positive changes after being asked to

reflect on their journey. These changes include shifting their mindset and values, stronger family bonds, and redefining a sense of normalcy and success (Gray et al., 2023; McGlinchey et al., 2024). Protective factors that reduce feelings of isolation and enhance connection are families who participate in support groups, peer mentorship, and inclusive education (Burton et al., 2017; Sutherland et al., 2024). Practitioners can further promote these positive changes in families by centring their approach on hope, empowerment, and strength-based approaches while also incorporating stress reduction techniques and behaviour management.

Chapter one of this capstone aligned theoretical frameworks with the exploration of the families' emotional and relational experiences with having a child diagnosed with a developmental disability. For instance, family systems theory supports the suggestion that the entire family unit becomes impacted from their child receiving a diagnosis of a developmental disability, in ways that effect their emotions, role shifting, boundaries, and patterns of interaction. Ambiguous loss theory provides insight on families non-finite and invisible experience of grief. This sense of loss is focused on how the family imagined their child's future to be before receiving the diagnosis. Ecological systems theory is important in contributing to the family's adaptation as it highlights significance on the mesosystem and exosystem, such as school systems and cultural values. The family resilience framework dives into how belief systems, adaptability, and communication influence coping in families. The meaning-making model compliments the family resilience framework by focusing on how families merge global beliefs with situational meaning following the diagnosis. Combining these frameworks provide a multidimensional lens for understanding how families find meaning in their journey of navigating their child's diagnosis of a developmental disability.

The purpose of a phenomenological review is for the research to be centred around the family's lived experiences of navigating their child's developmental disability diagnosis. The strengths of using a phenomenological approach come from its ability to place emphasis on the families' emotional processing and highlighting the subjectivity around coping, finding meaning, and resiliency. By synthesizing various qualitative studies, a phenomenological approach provides an in-depth review on different family structures within nuclear family systems.

Using a phenomenological approach has its limitations with being primarily reliant on secondary data. As such, there was an overrepresentation on data being received from Western, heteronormative, and middle-class families rather than diversity from studies across various countries and cultural groups. There was a lack of representation for members of the LGBTQ2S+ community. Although there was difficulty gathering data from different populations, the findings remain meaningful for practitioners to utilize in their practice and offer space with direction for future research.

Overall, the literature demonstrates that families undergo a complex journey of coping and finding acceptance of their child's diagnosis of a developmental disability. The journey is shaped through emotional, relational, cultural, and structural dynamics. Protective factors such as meaning-making, resilience, and engaging in reflective practices influence how families cultivate growth and connection through challenges such as stigma, systemic barriers, and role disruption. Additionally, there are gaps highlighted such as a lack of attention towards siblings, cultural responsiveness, and different family structures. These gaps points to future areas of research to further explore. Ultimately, the insights address the research question of: How do families of children with developmental disabilities cope and find acceptance with the diagnosis? Families cope by adaptation, meaning-making, and building on resilience, whereas acceptance evolves

over time as the family redefines values, strengthens bonds and connection, and reconstructs a new understanding of their child.

Applied Practices

The literature discussed the family resilience framework by Dr. Froma Walsh (2003), who developed a framework that addresses family belief systems, organizational patterns, and communication and problem-solving processes, and the meaning-making model by Park (2010). This capstone will utilize and expand on these models to create the family resilience and meaning-making support framework, which incorporates the same components as Walsh's model and Park's model, and it includes what the literature addressed as gaps. The models are still relevant in today's practice as they both guide counsellors' understanding of how families adapt to stressors, increase resilience, and integrate meaning in their lived experiences. Practitioners can use this framework to work with clients towards finding meaning and acceptance in supporting families who have children with a developmental disability. The framework is aimed at identifying the family's strengths, identity, and building connection. The family resilience and meaning-making model integrates and synthesizes evidence-based practices such as ACT, family systems theory, and principles from narrative therapy.

Family Resilience and Meaning-Making Support Framework

The family resilience and meaning-making support framework builds on previous frameworks identified through emotional regulation, systemic resilience, and cultural responsiveness, which are important domains for family adaptation. Walsh's (2003) family resilience framework identified the importance of belief systems and open communication in working towards resilience. Park's (2010) meaning-making-model identified the role of cognitive and emotional processes when reframing stressors. Current research reinforces that

family systems resilience, cultural identity, and connections within the community are listed as protective factors that support acceptance and long-term care for families of children with developmental disabilities (C. Lee et al., 2022; McGlinchey et al., 2024).

The family resilience and meaning-making support framework has three main pillars that form its foundation. The first is rooted in emotional processing and acceptance (Bakula et al., 2024), the second is family systems resilience (Dinç et al., 2024; Łada-Maśko et al., 2023), and the third is cultural responsiveness and community integration (Su et al., 2022; Udhmani et al., 2023).

Emotional Processing and Acceptance

The framework focuses on supporting families with managing emotional distress from receiving the news of their child having a developmental diagnosis. This pillar, emotional processing and acceptance, provides the family with support in understanding how to regulate the emotional impact that comes from receiving the news of the diagnosis (Gray et al., 2023; Su et al., 2022). It provides relief through emotions such as confusion and grief. This pillar draws from ACT and ambiguous loss theory. ACT is helpful to use in supporting families in aligning caregiving techniques with their values, along with working through emotional avoidance, and giving themselves the space to grieve and reflect (Bakula et al., 2024). Several strategies can be implemented for emotional processing and acceptance. These strategies include mindfulness-based parenting exercises; family storytelling and legacy work; and psychoeducation on grief, trauma, and resilience (Aeschlimann et al., 2024). Using these practices, families are supported in emotional release and cognitive reframing, working towards acceptance while maintaining their caregiving values.

There are a few theoretical connections made within this emotional processing and acceptance pillar. For instance, ACT aligns caregiver's personal values with their parenting actions. Secondly, ambiguous loss theory creates space for invisible grief around family's unmet expectations upon receiving the diagnosis of their child's developmental disability. Lastly, the meaning-making model provides an explanation on how distress presents itself in the family unit when there is misalignment in global beliefs and situational meaning of the diagnosis (Park, 2013). These theoretical connections align to create the pillar in the family resilience and meaning-making support model.

Family Systems Resilience

The framework examines the family unit's internal dynamics, addressing shifts in family roles, boundaries, and caregiving responsibilities. This pillar integrates family systems theory and highlights providing care and support for all members of the family, including extended family members and siblings (Dinc et al., 2024; Łada-Maško et al., 2024). Strategies to build family systems resilience involve incorporating regular family meetings/check-ins where they create goals. Another strategy is to provide programs for siblings to feel supported and expressive arts activities. Finally, providing intergenerational planning workshops is needed. By building on communication, connection, and flexibility, the families gain a sense of strength and resilience in navigating caregiving needs and creating emotional safety (Jacobson, 2025).

This pillar stems from theories such as family systems theory, family resilience theory, and ambiguous loss theory. Family systems theory is used by viewing the family as a unit in which each member influences other members of the family emotionally (Watson, 2012). Family resilience theory provides insight on healing by placing emphasis on belief systems, communication, and adaptability (Walsh, 2003). Ambiguous loss theory offers the space for the

family to find unity in each other while honouring the individual experience of how they make sense of loss.

Cultural Responsiveness and Community Integration

The family resilience and meaning-making support framework focuses on acknowledging that cultural values shape the way a family perceives disability, caregiving, and support-seeking. The cultural responsiveness and community integration pillar is grounded in ecological systems theory as well as research on cultural humility. The practices that practitioners must uphold are to engage in cultural humility that recognizes collectivist and individualist ideologies, spiritual belief systems, and lived experiences (C. Lee et al., 2022; Su et al., 2022). Strategies to incorporate cultural responsiveness may include cultural brokering and using faith-based collaborations (Shen & Gershwin, 2024). Additionally, encouraging peer mentorship from families who share similar backgrounds and providing tools to navigate through community, financial, and legal supports are needed. Connecting families to support systems reduces the feeling of isolation, promotes resilience, and creates long-term support networks (Holt-Lunstad, 2024)

This pillar is grounded in a few theories such as ecological systems theory, connecting to cultural humility, and family resilience theory. Ecological systems theory offers families with being situated within social, political, and cultural systems on navigating their child's diagnosis of a developmental disability (Guy-Evans, 2024). Cultural humility builds on this pillar as it ensures practitioners remain curious and avoid pathologizing caregiver practices that may be rooted in their cultural traditions (Su et al., 2022). Finally, family resilience theory ties this pillar together by integrating a strength-based approach with building diversity in cultural belief systems (Walsh, 2003).

Practical Implications

The family resilience meaning-making framework can be accessible to be used by counsellors, teachers, support workers, and social workers. The framework can be adapted into family therapy through structured sessions that provide meaning-making exercises between parents and siblings. It can be offered in various support groups and be adapted to include different culturally informed modules. Creating workshops in the community to promote family resilience and meaning-making towards acceptance with a child who has a developmental disability can offer intergenerational care planning and reduce stigma. Additionally, support workers can be educated and trained to work with families using a trauma-informed and culturally sensitive approach. The purpose of creating a framework that incorporates family resilience and meaning-making is to emphasize healing as a collective process. It can create opportunities for practitioners to practice holding space for uncertainty, grief, and culture that are present in the caregiving experience.

By using a framework that teaches family resilience and meaning-making, there is a response to some areas, addressing the gaps in the literature. For instance, it responds to the lack of interventions provided to the siblings of a child with a developmental disability who also experience an emotional impact (Fatma et al., 2024). This strategy also works at being adaptable culturally to address the barriers of current models that do not respond to differences in individualistic and collectivist cultures (Su et al., 2022). It also identifies and addresses future planning and intergenerational caregiving roles, which can sometimes be neglected in other support models (Bahri et al., 2023; Namkung et al., 2020). Finally, this strength-based approach addresses the gap that pathologizes stress and neglects meaning-making or growth (Gray et al., 2023). Integrating all of these components addresses the gaps in the literature and provides an

inclusive and culturally informed practice using a holistic framework to meet the needs of families who are seeking meaning-making and acceptance of their child's diagnosis of a developmental disability.

Counsellors must adhere to the highest ethical standards when working with families of children with developmental disabilities. For instance, they must consider issues around informed consent ensuring that parents and their children understand the purpose and process of engaging in family counseling (Canadian Psychological Association [CPA], 2017). Counsellors must also be mindful and sensitive to power imbalances and vulnerability as the families may develop a dependence on seeking guidance. Additionally, children with developmental disabilities are legally and ethically recognized as part of the vulnerable population (CPA, 2017). From an ethical standpoint, counselors must adhere to the ethics of beneficence and nonmaleficence when supporting parents through meaning-making by also prioritizing the best interests of the child (CPA, 2017). By engaging in ethical practice, professionals must undergo ongoing professional development trainings. For instance, counselors applying this framework should engage in trainings around disability studies, trauma informed care, and family resilience models as well as obtain ongoing clinical supervision to provide ethical practice (CPA, 2017).

Reflections

The journey of completing this capstone has expanded my personal and professional growth and learning. When I began this project, I held a strong personal bias on how family systems interact and work towards resiliency. I also noticed that I had many questions that I was searching answers for such as how some families exhibit low levels of resiliency while taking care of a child with a developmental disability. I believed that resiliency was about maintaining strength while facing adversity. However, as I dove into the research, I realized that I had to

change my definition on what resiliency means as well as caretaking. The literature broadened my perspective on resiliency as being a concept that is about adapting to this situation in meaningful ways, whether that be through struggles, grief, or uncertainty of the future. Cultural frameworks also challenged how I view different responses to disability, specifically when caregivers experienced stigma or cultural and societal expectations.

My lens was already formed due to my positionality as a sister who has a sibling with a developmental disability. However, through this research, I developed an increased awareness of my biases, specifically with my assumptions of universal caregiver responses. The research taught me that there are many ways of coping, processing, and adapting to environmental and situational stressors. For instance, some families seek meaning through faith, while others seek it through advocacy, or reflection and connection. By expanding and challenging my biases, my future work as a clinician has shifted my perception of how different clients find meaning through their coping styles. My aim as a practitioner is to provide a safe space for families and siblings of a child with a developmental disability. This space would be meant for them to share grief with no judgement, celebrate their unique way of exhibiting resilience, and express curiosity and openness to each family's story, culture, and values.

Conclusion

This capstone project contributes to literature which identifies and recognizes the complexities of a family's response to a child's developmental disability. There is a comprehensive understanding of the concepts of meaning-making and acceptance processes through synthesizing the key themes of emotional processing, role shifts, cultural influences, sibling impact, and systemic barriers. By combining models to create a proposed family resilience and meaning-making support framework, practitioners can utilize a strength-based,

inclusive, and culturally responsive model in their practice with clients. Practitioners can support families by using a holistic approach to honor the resilience, grief, and compassion that families carry, moving away from deficit-based narratives. By using this technique, not only is the individual child with a developmental disability being supported but also the family system—they are strengthened as a whole.

This capstone explored the following research question: How do families of children diagnosed with a developmental disability find meaning and acceptance from the diagnosis? Each chapter has contributed to analyzing this question through a conceptual, empirical, and applied foundation in order to understand the lived experiences of families and the support that can cultivate resilience. Chapter one introduced the research question and provided an overview of the topic for studying meaning-making and acceptance within families. It provided a formal definition of developmental disability as well as the significance of this issue in the counseling practice. Chapter two reviewed the literature in depth to reveal how families experience emotional, relational, and structural challenges as well as highlight ways to achieve resilience and meaning-making. The chapter provided a critical examination on parental perspectives, sibling experiences, marital dynamics, cultural influences, coping strategies, and systemic barriers. Gaps in the literature were also identified such as limited research on siblings, non-traditional families, and cultural responsiveness. These were seen as opportunities for future research. Chapter three integrated the findings from the literature review and created applied practice by using the family resilience and meaning-making support framework that expands on Walsh's (2003) family resilience framework and Park's (2013) meaning-making model. The framework addresses gaps that were identified in the literature by incorporating evidence-based practices such as ACT, family systems theory, and narrative therapy. Overall, the capstone

highlights that acceptance is not one single process but rather an ongoing relational process that is shaped through emotional processing, family resilience, as well as cultural and systemic contexts.

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