Promoting Family Resilience through ASD Diagnostic Assessment: An Enhanced Critical Incident Technique Study

By

Kristy Lorraine Dykshoorn

A thesis submitted in partial fulfillment of the requirements for the degree of

Doctor of Philosophy

In

Counselling Psychology

Department of Educational Psychology

University of Alberta

Abstract

This study will attempt to bridge the gap between the theoretical knowledge of family resilience and the practical implementation of this knowledge. The primary objective, in conducting this study, is to better understand how families with children with ASD can capitalize on their strengths by promoting family resilience. Interviews were conducted with 12 caregivers of children recently diagnosed with ASD in Alberta, Canada. Enhanced Critical Incident Technique (ECIT) was used to analyze the interview data. Data analysis resulted in 18 helping categories, 13 hinder categories, and 10 wish list categories that encapsulated the 274 incidents/wish items identified by the participants. These categories were then further divided by relevance for professionals (Part I) and for parents/families (Part II). The categories in Part I were synthesized with existing literature to conclude, (a) practical and resource-based recommendations, (b) emotional support recommendations, and (c) systemic recommendations for professionals. The categories in Part II were also presented within the context of the current literature and external resilience-enhancing and resilience-challenging influences are presented, as well as internal resilience-enhancing and resilience-challenging influence are discussed.

Preface

This dissertation is an original work by Kristy Lorraine Dykshoorn. The study, of which this dissertation is part of, received research ethics approval from the University of Alberta Research Ethics Board, "Promoting familial resilience through ASD diagnostic assessment: An enhanced critical incident technique study", No. Pro00062604, May 24, 2016 (amendments approved March 30, 2017, April 5, 2017, November 9, 2017, & March 6, 2018).

Dedication

This dissertation is dedicated to the amazing moms and dads in my life, especially my own mom & dad, and my brothers and sisters who have become incredible parents to my beautiful nieces and nephews. May you find endless resilience as you journey through the most difficult and rewarding task a person can take on.

Acknowledgements

There are so many people who have contributed both formally and informally to this project. I would be remiss if I didn't name and thank each one and also acknowledge my gratitude to the Social Sciences and Humanities Research Council of Canada for funding this project with a three-year doctoral award.

First, to Dr. Damien Cormier, thank you for your support, kindness, and guidance. Four years ago, you took a chance on me as your first PhD student and I have been grateful for that decision ever since. You have gifted me with so much knowledge and wisdom over the years and I have come to see you as a mentor, colleague, and friend. Thank you!

To my supervisory and examiner committee, Dr. William Hanson, Dr. Christian Rinaldi, Dr. William Whelton, Dr. Rebecca Hudson-Breen, and Dr. Adam McCrimmon, thank you for your insights and suggestions during the proposal, writing, and defense process. Your interest in the project is a reminder of the value of my work and that inspires me to continue this work in the future.

Thank you to my mom & dad, siblings & siblings-in-law, and nieces & nephews. Without your endless encouragement and support, I would never have made it through the last six years. You have reminded me to stay strong and courageous when I felt like it was all too much, celebrated the successes with me, and have been my safe haven away from the chaos on countless occasions. Shellie and Jerry, thank you for taking care of me every Sunday for the last five years. You are my home away from home and my calm in the storm. Mom and dad, without you I wouldn't have an intimate knowledge of resilience. You taught me to be resilient through your profound faith in God's plan, the strength we have in family, and the value of getting a little dirt under our fingernails.

To Jennifer and Rachel, you started as cohort members, became colleagues, and have reached the point of being two of my best friends. Thank you for supporting me, listening to my frustrations, and celebrating with me. Our monthly book clubs kept me going and the memories we’ve made over the last five years will last a life time.

Mark, my partner and best friend, thank you for the endless support and encouragement and for the confidence you have in me and my abilities. I thank God for you every day.

Lastly, and certainly not least, thank you to my incredible participants. Thank you for trusting me with your stories, for sharing your truth, and for allowing your wisdom to be passed on to those who come after you. Keep being the amazing mothers and advocates that you are!

Table of Contents

List of Tables

CHAPTER ONE: Introduction

The following chapters are intended to bridge the gap between positive psychology research and Autism Spectrum Disorder (ASD) research. Both positive psychology and ASD have a solid presence within the psychology research arena (Lopez, Pedrotti, & Snyder, 2018; Matson & LoVullo, 2009). Significant attention has been given to these two branches of psychology and the professional knowledge base is extensive though, by no means, exhaustive. As will be demonstrated, there has been limited application of the positive psychology framework to ASD research; however, the overlap between the two fields could be increased considerably, given that one can inform the other.

Those whose research focuses on positive psychology aim to evaluate topics like emotional intelligence, compassion, engagement, wellbeing, positive affect, resilience, and life satisfaction (Kim, Doiron, Warren, & Donaldson, 2018). They investigate various populations using a positive psychology orientation, including marginalized populations, individuals with PTSD, refugees, indigenous peoples, those with HIV/AIDS, and natural disaster survivors. The positive psychology research community has influenced the lives of individuals, groups, and nations by exploring the themes of resilience after traumatic events/disease/injury, positive experiences of marginalized populations, indicators of happiness across cultures, and the balance between positive and negative perspectives in psychology (Kim et al., 2018, p. 62 & 63).

Programs of research related to studying ASD has grown and expanded to include topics such as genetics, perception/cognition, neurobiology/physiology, treatment, comorbidity, social skills, development, challenging behaviours, theory of mind, and epidemiology (Matson & LoVullo, 2009). More specifically, psychology-based ASD research has included investigations into the negative impact of ASD on caregivers (Baxter, Cummins, & Yiolitis, 2000; Doron &

Sharabany, 2013), siblings (Karst & Van Hecke, 2012; Nixon & Cummings, 1999; Rodrigue, Morgan, & Geffken, 1993), and the family as a whole (Lord & Bishop, 2010; Morrison, Sansosti, & Hadley, 2009; Woodgate, Ateah, & Secco, 2008) which will be explored more fully in the following chapters. Nevertheless, it is evident that the majority of ASD research has been deficit-oriented and has focused on the increase in maladaptive behaviours, coping, and functioning of these individuals and their families.

Despite the seemingly very different research focuses of the two research areas, there has been some overlap. Primarily, the positive psychology framework has been applied to ASD populations in two areas. First, strength-based approaches have been discussed, developed, and encouraged in working with children with ASD (Steiner & Gengoux, 2018; Timmons & Ekas, 2018). Second, the positive psychology framework has been applied to the ASD research field in pursuit of better understanding in two specific areas: (a) how loved ones of individuals with ASD successfully manage negative ASD-related consequences, outcomes, and situations (Bekhet, Johnson, & Zauszniewski, 2012b; Halstead, Ekas, Hastings, & Griffith, 2018); and, (b) more recently, how they function after those adverse situations are over or managed (Wayment, Al-Kire, & Brookshire, 2018). The construct most relevant to these two applications is resilience. Resilience is defined as "the potential to exhibit resourcefulness by using available internal and external resources in response to different contextual and developmental challenges" (Pooley & Cohen, 2010, p. 34).

The construct of resilience in families of individuals with ASD has been investigated for some time; beginning with an exploration of their protective factors in the early 2000s (Harris & Glasberg, 2003) and then later exploring the presence of resilience for families with ASD (Bekhet, et al., 2012b). Traditionally, within the ASD research literature, protective factors and resilience have been viewed as an innate characteristic or a trait that these families either possess or lack rather than a skill or quality that can be promoted, fostered, instilled, or bolstered. Now that the presence and value of resilience has been identified in individuals with ASD and their families, the next important steps are to explore specific ways resilience can be promoted within the family, to make recommendations for facilitating family resilience, and to evaluate the overall impact of resilience on quality of life. Without this evolution in ASD research, the ASD research community is unable to take their theoretical knowledge about the importance of resilience to a more advanced understanding of the specific implications of resilience, or lack thereof, on the family in the presence of ASD and ways in which this valuable quality can be encouraged. The following study (chapters two, three, and four) will provide clear direction about how to take the theoretical knowledge of family resilience to a practical application of deeper research knowledge and will provide preliminary findings about how resilience can be promoted within the family of newly diagnosed children with ASD.

Relevance to Counselling Psychology

Counselling psychology, as a profession, has had a difficult time defining itself in relation to the other disciplines within psychology (Gelso & Fretz, 2001). Much of the difficulty scholars have had in defining counselling psychology stems from the psychologists' highly diverse skills applied to a wide range of contexts. Counselling psychologists engage in a broad range of jobs, settings, and activities. According to Gelso and Fretz (2001), despite the setting or activity, counselling psychologists have consistently played three major roles: "the remedial, the preventative, and the developmental" (p. 4). Counselling psychologists focused on their remedial role will be primarily concerned with helping individuals, families, or groups to remedy specific concerns, issues or problems. Conversely, the preventative role, as the name suggests, is one in which the counselling psychologists attempts to prevent negative or adverse experiences *before* they happen. Finally, a psychologist in the developmental role is focused on enriching or enhancing the individual, family, or group wellbeing, experiences, or life, in general (Gelso & Fretz, 2001). Within the current study, all three roles are considered. The developmental role is addressed directly, while the remedial and preventative roles are addressed more indirectly.

Individuals who have recently gone through an ASD diagnostic assessment and have received a diagnosis have already faced a number of the difficulties. Participants will have an opportunity to discuss their experience, think about and discuss the positive experiences, and have their negative experiences heard and respected during the interview process. Although these steps will not completely remedy the difficulties these participants are facing, it may help them to identify the ways in which resilience can and has remediated the outcomes of adverse and stressful experiences. Referring to the counselling psychologist's preventative role, researchers have demonstrated that caregivers of individuals with ASD experience a number of difficulties, adverse experiences, and negative consequences (i.e., Baxter, et al., 2000; Benson & Karlof, 2009; Brobst, Clopton, & Hedrick, 2009; Doron & Sharabany, 2013; Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011; Higgins, Bailey, & Pearce, 2005). Through this study, the anticipated adverse effects of caring for someone with ASD are acknowledged and positive psychology and resilience are suggested as a valid approach through which the negative consequence can be lessened or prevented all together.

Gelso and Fretz (2001) describe the developmental role as a step beyond prevention. This role is addressed directly in the following chapters. Through the research call to action paper and the two empirical papers, a strong argument for the use of positive psychology and resilience in the lives of individuals affected by ASD will be made. By focusing on positive psychology, as a lens through which to engage in research, counselling psychologists can better understand the ways individuals with ASD and their families thrive and experience life satisfaction or fulfillment. Specifically, resilience, as a core construct within positive psychology, is one possible characteristic or quality that allows this population to successfully navigate the challenges associated with ASD (Bekhet et al., 2012b). Resilience is fostered in many different ways, including internal resources (such as positive emotions; Bekhet, Johnson, & Zauszniewski, 2012a; Cohn et al, 2009) and support from professionals, friends, and family (Brobst, Clopton, & Hedrick, 2009; Carter, Martinez-Pedraza, & Gray, 2009; Ekas, Lickenbrock, & Whitman, 2010; Hall & Graff, 2011; Tobing & Glenwick, 2007). By applying this known research to an ASD-specific population, researchers can begin to understand the unique ways resilience is fostered and used to promote increased overall well-being. As a result, the developmental role is actualized in a population that has often been approached by researchers seeking to fulfill the remedial role.

Study Objectives

Upon review of the limited positive psychology literature, I discovered a noticeable gap. Although parental and family resilience has been researched in families with individuals with ASD, there have been no investigations to better understand the specific factors that promote or harm the development and endurance of resilience in families with children with ASD. There has been limited research on how parental resilience influences a child with ASD and very little research informing practitioners about how they can promote and/or influence caregiver resilience during an ASD assessment. First, the call to action component of this study provides a comprehensive look at how positive psychology can be applied to various populations, highlights the limited positive psychology research investigating the lives of individuals affected by ASD, and provides a possible starting point for a new program of research focusing on understanding how to enhance resilience and life satisfaction for those with ASD. Additionally, this call to action provides a sound rationale and justification for the research investigation outlined in chapters two and three. The empirical study provides caregivers with the opportunity to discuss their experiences with the ASD diagnostic assessment and disseminate useful, practical, and important information to psychologists and physicians about how to better instil and/or enhance resilience in the families they are working with and to encourage other caregivers embarking on the ASD diagnostic journey.

Advocacy and speaking out in support of those who find it difficult to do so for themselves is of utmost importance within the counselling psychology field (Lee & Rodgers, 2009). Advocacy is both an obligation and an honour. Given the extra burden on a caregiver of a child with ASD, self-advocacy may seem like an impossible task, but well-balanced research findings can inform advocacy efforts. Through this study, researchers will be challenged to view individuals affected by ASD differently; to see them for the potential they possess rather than their deficits and weaknesses. The ultimate purpose of this study is to encourage for a more balanced view of this population; to encourage researchers to adopt a positive psychology orientation; and, to begin to develop a research base that honours, respects, and understands this population's ability to thrive and experience life satisfaction.

References

Baxter, C., Cummins, R., & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual and Developmental Disability, 25*, 105-118. doi: 10.1080/13269780050033526

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012a). Effects on resilience of caregivers of persons with autism spectrum disorder: The role of positive cognitions. *Journal of the American Psychiatric Nurses Association, 18*, 337-344. doi: 10.1177/10788390312467056

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012b). Resilience in family members of persons with autism spectrum disorder: A review of the literature. *Issues in Mental Health Nursing, 33*, 650-656. doi: 10.3109/01612840.2012.671441

Benson, P. R. & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders, 39*, 350-362. doi: 10.1007/s10803-008-0632-0

Brobst, J. B., Clopton, J. R., & Hedrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple’s relationship. *Focus on Autism and Other Developmental Disabilities, 24*, 38-49. doi: 10.1177/1088357608322699

Carter, A. S., Martinez-Pedraza, F. D. L., & Gray, S. A. O. (2009). Stability and individual change in depressive symptoms among mothers raising young children with ASD: Maternal and child correlates. *Journal of Clinical Psychology, 65*, 1270-1280. doi: 10.1002/jclp.20634

Doron, H., & Sharabany, A. (2013). Marital patterns among parents to autistic children. *Psychology, 4*, 445-453. doi: 10.4236/psych.2013.44063

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 1274-1284. doi: 10.1007/s10803-010-0986.y

Gelso, C. & Fretz, B. (2001). *Counselling psychology* (2nd ed.). Belmont, CA: Wadsworth Group.

Hall, H. R. & Graff, J. C. (2011). The relationships among adaptive behaviours of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing, 34*, 4-25. doi: 10.31109/0146-862.2011.555270

Halstead, E., Ekas, N., Hastings, R. P., & Griffith, G. M. (2018). Associations between resilience and the well-being of mothers of children with autism spectrum disorder and other developmental disabilities. *Journal of Autism and Developmental Disorders, 48*, 1108-1121. https://doi.org/10.1007/s10803-017-3447-z

Harris, S. & Glasberg, B. (2003). *Siblings of children with autism: A guide for families.* Bethesa, MD: Woodpine Press.

Hartley, S. L., Barker, E. T., Seltzer, M. M., Greenberg, J. S., & Floyd, F. J. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal on Intellectual and Developmental Disabilities, 116*, 81-95. doi: 10.1352/1944-7558-116.1.81

Higgins, D., Bailey, S., & Pearce, J. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism, 9*, 125-137. doi: 10.1177/1362361305051403

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of Autism Spectrum Disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychological Review, 15*, 247-277. doi: 10.1007/s10567-012-0119-6

Kim, H., Doiron, K., Warren, M. A., & Donaldson, S. I. (2018). The international landscape of positive psychology research: A systematic review. *International Journal of Wellbeing, 8*, 50-70. Doi: 10.5502/ijw.v8il.651

Lee, C. C. & Rodgers, R. A. (2009). Counselor advocacy: Affecting systemic change in the public arena. *Journal of Counseling & Development, 87*, 284-287. doi: 10.1002/j.1556-6678.2009.tb00108.x

Lopez, S., Pedrotti, J. T., & Snyder, C. R. (2018). *Positive psychology: The scientific and practical explorations of human strengths* (4th ed.). Thousand Oaks, CA: Sage Publications Inc.

Lord, C., & Bishop, S. L. (2010). Autism spectrum disorders: Diagnosis, prevalence, and services for children and families. *Society for Research in Child Development, 24*, 1-21.

Matson, J. L., & LoVullo, S. V. (2009). Trends and topics in autism spectrum disorders research. *Research in Autism Spectrum Disorders, 3*, 252-257. doi: 10.1016/j.rasd.2008.06.005

Morrison, J. Q., Sansosti, F. J., & Hadley, W. M. (2009). Parent perceptions of the anticipated needs and expectations for support for their college-bound students with Asperger's' syndrome. *Journal of Postsecondary Education and Disability, 22*, 78-87.

Nixon, C. L., & Cummings, E. M. (1999). Sibling disability and children's reactivity to conflicts involving family members. *Journal of Family Psychology, 13*, 274-285.

Rodrigue, J. R., Morgan, S. B., & Geffken, G. R. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology, 19*, 371-379. doi: 10.1207/s15374424jccp1904_9

Steiner, A. M., & Gengoux, G. W. (2018). Strength-based approaches to working with children with ASD. In M. Siller, & L. Morgan (Eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism: Autism and Child Psychopathology Series* (pp. 155-168). Springer, Cham. https://doi.org/10.1007/978-3-319-90994-3_10

Timmons, L., & Ekas, N. V. (2018). Giving thanks: Findings from gratitude intervention with mothers of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 49,* 13-24. https://doi.org/10.1016/j.rasd.2018.01.008

Tobing, L. E. & Glenwick, D. S. (2007). Predictors and moderators of psychological distress in mothers of children with pervasive development disorders. *Journal of Family Social Work, 10*, 1-22. doi: 10.1300/J039v10n04_01

Wayment, H. A., Al-Kire, R., & Brookshire, K. (2018). Challenged and changed: Quiet ego and posttraumatic growth in mothers raising children with autism spectrum disorder. *Autism, 0*, 1-12. doi: 10/1177.1362361318763971

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative Health Research, 18*, 1075-1083. doi: 10.1177/1049732308320112

CHAPTER TWO: Autism Spectrum Disorder Research: Time for Positive Psychology

The use and acceptance of positive psychology in the broader research community has steadily increased over the past two decades (Seligman & & Csikszentmihalyi, 2000). To date, however, the use of positive psychology frameworks to investigate the lives of individuals with Autism Spectrum Disorder (ASD) and their families is limited to the role of pre-established protective factors in managing stressful situations. The following paper will serve as a call to action for ASD researchers. The theoretical framework of positive psychology will be described in detail, followed by a discussion on ASD and family systems. Finally, an argument for further investigation into the role of positive emotions and resilience in the life satisfaction of those with ASD and their families will be presented as an important positive psychology research program of study.

Positive Psychology

Positive psychology is described as the systematic study of positive experience and individual characteristics, and the associations that promote their development (Duckworth, Steen, & Seligman, 2005). Pre-World War II, psychology was largely a restorative discipline, based on psychopathology and the medical model (Maddux, 2002; Maddux, Gosselin, & Winstead, 2005; Maddux, Snyder, & Lopez, 2004). Positive psychology developed out of the post-World War II culture of healing, repairing damage, and pathology (Seligman & Csikszentmihalyi, 2000). The previous preoccupation with psychopathology neglected healthy societies and the thriving individual’s subjective experiences of “well-being, contentment, and satisfaction (in the past); hope and optimism (for the future); and flow and happiness” (in the present; Seligman & Csikszentmihalyi, 2000, p. 5). The theoretical foundations of positive psychology focus on building individual strengths, rather than identifying and correcting weaknesses (Duckworth et al., 2005). Individual strengths may include concepts such as love, happiness, courage, perseverance, satisfaction, forgiveness, wisdom, and resilience (Seligman & Csikszentmihalyi, 2000).

Seligman and Csikszentmihalyi (2000) highlighted the importance of positive psychology in prevention. Prevention has become one of the primary goals of psychology and psychological research. It focuses on ways in which professionals can help individuals avoid mental health problems. The traditional disease model does not formally provide insight into prevention, but the systematic and deliberate focus on building up the strengths of an individual has been found to be the most effective method for preventing mental illness (Seligman & Csikszentmihalyi, 2000). For example, Seligman and Csikszentmihalyi (2000) urged psychologists who work with families to create a therapeutic culture that seeks out, nurtures, and amplifies these strengths, which likely will have a positive effect on the family's long-term functioning, emotional well-being, mental health, cohesiveness, and resilience.

Positive psychology researchers seek to create a more balanced body of literature. A disproportionate focus on negative aspects of life has led to an unbalanced research field, which undervalues the positive aspects (Wood & Tarrier, 2010). Although the consideration of atypical and typical developmental experiences of those with various mental disorders (Cicchetti & Toth, 1998; Sroufe, Carlson, Levy, & Egeland, 1999) has been discussed, it has yet to be expanded to individuals with ASD and their families. Although it may be difficult to identify topics as either positive or negative, positive psychology focuses on the characteristics that allow individuals to thrive, be successful, and manage difficult life events (Wood & Tarrier, 2010). Living a positive life is not merely the absence of negative emotions, thoughts, and experiences, but rather involves a completely separate psychological process (Duckworth et al., 2005). As a result, discovery and empirical research into these psychological processes is in its early stages; measures are still being developed and evaluated, longitudinal studies have yet to be completed, and therapeutic interventions have yet to be empirically supported (Duckworth et al., 2005). As such, there is a need to expand this perspective to include those with ASD and their families. As will be seen below, individuals with ASD have many atypical developmental experiences and their families deal with them in various ways, but there is also tremendous capacity for these individuals and their families to have typical experiences of love, hope, happiness, optimism, resilience, satisfaction, and other positive life events.

Autism Spectrum Disorder

Leo Kanner, a child psychologist, identified autism as a childhood medical disorder in 1943. In the inaugural article, Kanner (1943) described 11 case studies based on his work with eight boys and three girls. He used the 11 case studies to demonstrate the individual differences found in children with "autistic disturbances" but identified the fundamental similarity as "the children's inability to relate themselves in the ordinary way to people and situations from the beginning of life" (Kanner, 1943, p. 242). According to Coleman (1989), Kanner felt that the term *autistic* best described the "extreme aloneness from the beginning of life and an anxious, obsessive desire for the preservation of sameness" that the children had in common (p. 3). Kanner noted that all eleven children lacked typical physical reciprocity (i.e., eye gaze and shoulder shrugging when an adult caregiver lifts the child up). Additionally, he highlighted the common communication deficits; indicating that three of the children never acquired language and the other eight learned to speak at the typical age or after some delay, but did not possess mature, spontaneous conveyance of meaning. Finally, Kanner highly emphasized the children's general disinterest in other people. The final paragraph of Kanner's article began a trend of parent blaming. The term *Refrigerator Mother* was coined as a description of the types of mother's that cause children with autism (Sanua, 1986). Fortunately, science has since refuted this caregiver-blaming trend (Coleman, 1989). Despite Kanner's emphasis on the specific deficits these eleven children were facing and his overall negative impression, he made a point of noting the "cognitive potentialities", "intelligent physiognomies", "serious-mindedness", and "anxious tenseness" observed in these children (Kanner, 1943, p. 247). It is important to note, however, that these characteristics can only conclusively describe the eleven case studies Kanner presented. Autism presents in a number of different ways and, as Stephen Shore, an adult with autism, explained, "if you've met one person with autism, you've met one person with autism".

According to the Centre for Disease Control and Prevention (CDC; 2014), Autism Spectrum Disorder occurs in about 1 in 59 children, a prevalence rate of 1.68%, which has increased from 1 in 150 in 2000. Additionally, ASD is roughly four times more likely to be diagnosed in boys than girls (CDC, 2014). According to the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-5; American Psychiatric Association [APA], 2013), ASD has been categorized as a "Neurodevelopmental Disorder" (p. 31). Under this umbrella term, there are several disorders that have onset during the same critical developmental period. In general, children with ASD, display deficits in social interaction, communication, and behavioural patterns. More specifically, children with ASD display: (a) persistent deficits in communication and social interaction across several contexts; (b) restricted, repetitive patterns of behaviour, interests, or activities; (c) symptoms that must be present in the early developmental period; and, (d) symptoms that cause clinically significant impairment in social, occupational, or other important areas of current functioning (APA, 2013, p. 50-51).

The aforementioned symptoms can manifest in a variety of ways depending on “autistic condition, developmental level, and chronological age”, which is why the disorder is considered a “spectrum” (APA, 2013, p. 53). This spectrum of symptoms does not occur in isolation; rather, the symptoms often occur within the context of a family unit. Difficulties related to sleep, eating, aggressive behaviours, communication, difficulty changing routine, and repetitive behaviours (to name a few) can disrupt each member of the family (Glass, 2001).

Family Systems and ASD

The Family Systems approach to psychological research values each family member’s subjective understanding of their reality (Pulg, Koro-Ljungberg, & Echevarrla-Doan, 2008). Family systems theorists suggest that all parts of the family unit are equally important in the development and socialization of family (Padilla-Walker, Harper, & Jensen, 2010). Further, the development and socialization of the family is influenced by the social context and system in which the family lives (Pulg et al., 2008). Finally, the importance of caregivers in the life, development, and well-being of children is consistent with family systems models of counselling and psychological research (Broderick, 1995). Despite the relative inward focus of children with ASD, it can be assumed that the systemic context in which the child is being raised will have an impact on the child’s overall development (Kelly, Garnett, Attwood, & Peterson, 2008). Because of the unique characteristics and qualities of children with ASD, existing family systems research needs to be considered with caution and new ASD-specific family systems research needs to be developed.

Family systems theory was identified and described as a result of the emergence of family therapy, which gained popularity after World War II (Combrinck-Graham, 1990). At the time, psychologists and psychiatrists became increasingly interested in the many influences on human behaviour and wondered what would happen if the whole family engaged in treatment together. Beginning as an experiment, psychologists would invite the whole family into therapy to observe and gain a better understanding of the interactions and family dynamics. Naturally, psychologists began developing their own theories of family therapy and independent schools began to emerge (e.g., psychodynamic family therapy, Bowen systems therapy, Satir family therapy; Combrinck-Graham, 1990). Despite the various forms of family therapy available, the family systems' influence on research has remained largely united under the assumption that an individual's system (family or social) significantly influences his or her personal development. Consequently, research projects that adhere to the family systems approach focus on the interconnectedness of the family unit and seek to understand the influence of one or more family member(s) on the other(s). It can, therefore, be inferred that the experiences, coping ability, mental health, and social support of caregivers' influence the functioning of the entire family unit; and thus, the psychological health of an individual is directly connected to the psychological health of the family as a whole.

Caregivers. Raising a child is challenging and trying for all caregivers and, when a child has a developmental disorder, the difficulties and challenges are increased. Caregivers are the responsibility holders of the family unit and, arguably, hold the most influence over the success of the family. Caregivers are expected to face a poorly understood behavioural, cognitive, and relational childhood disorder that could include any of the previously outlined symptoms and deficits. The roles caregivers play is pivotal to the success of not only the child, but of the whole family unit.

Although the term *parenting* is widely accepted and understood both among scholars and lay-people alike, no one has yet developed a comprehensive and accepted definition of parenting

(Smith, 2011). Typically, parenting includes elements of promoting language and learning, fostering of a stimulating home environment, warmth, positive encouragement, and promotion of beliefs and/or attitudes. Bornstein (2001) offers this description: "parenting beliefs include perceptions, expectations, attributions, attitudes, knowledge, ideas, goals, and values about all aspects of child-rearing and child development" (p. 2). These beliefs do not provide a definition of parenting, but they do provide insight into the thoughts that shape basic parenting behaviour. Although the exact nature and behaviours associated with the above characteristics may manifest differently in different families, caregivers can relate to and understand parenting behaviours categorized in this way. Several factors influence the way caregivers come to parent their children. For example, socialization of the caregiver, warmth and affection, parental control (Maccoby & Martin, 1983), characteristics of the child, child temperament, reciprocal interaction (Rutter, 1979), familial relationships (Hinde & Stevenson-Hinde, 1987), and caregiver mental well-being (Radke-Yarrow, 1999) all influence the parenting behaviour of a caregiver. The complex nature of parenting (e.g., parental personality, child characteristics, parental developmental history, marital satisfaction, social network support, economic status, and educational status) makes it nearly impossible to evaluate all aspects of the influence caregivers have in the family atmosphere (Smith, 2011). This is why researchers must break down the factors of parenting and evaluate them separately.

The role caregivers play in the development of their children's social and personal identity has been widely researched. Caregivers are the first and most influential relationships children encounter and, thus, caregivers have the ability to shape and promote children's well-being. For example, factors associated with family function (i.e., family relationship and an emphasis on personal growth) can promote social competence and reduce negative behaviours in children (Dyson, 2003). That being said, caregivers can only be effective at parenting when their own emotional well-being is cared for, which is equally true for caregivers of children with ASD.

Caregivers of children with ASD seem to have more difficult marital and/or intra-familial relationships (Baxter, Cummins, & Yiolitis, 2000). Doron and Sharabany (2013) found that the severity of a child's ASD symptoms did not correlate with marital satisfaction or emotional well-being. Nevertheless, it was found that when couples received satisfying support from family and friends, the marital relationship was perceived as closer and the emotional well-being of both members of the couple was healthier. When marital satisfaction is higher, caregivers are more equipped to parent as a unified team, and thus more effective at parenting in a way that supports and promotes healthy development in their children (Doron & Sharabany, 2013).

Caregivers play an integral role in the coping ability of a family unit. Without caregivers' ability to model, facilitate, and support the positive functioning of the family, the family is less likely to thrive. Without a thriving family unit, the challenges associated with having a family member with ASD are more difficult to manage and may have more significant consequences.

ASD and the family. In 1994, Norton and Drew highlighted the lack of research discussing the influence of ASD on family relationships (e.g., marital, sibling, and parent-child). However, because approximately 85% of adults with ASD possess cognitive and/or adaptive deficits that prevent independent daily living, family members (e.g., siblings or caregivers) are necessary for long-term care/assistance (Volkmar & Pauls, 2003). Additionally, the changing conceptualization of ASD, unclear etiology, and constantly adapted treatment recommendations leaves family members guessing about the best course of action for their family (Rutter, 2011).

As a result, families may be less optimistic, hopeful, and certain about their own futures, which may, in turn, affect their personal well-being and mental health (Karst & Van Hecke, 2012).

Research has largely drawn attention to the negative consequences and outcomes of living with a child with ASD. Pottie and Ingram (2008) highlighted that living with a child with ASD negatively influences families despite symptom severity or time of diagnosis. Each member of the family can be influenced in different ways. Families with ASD, for example, are more susceptible to family conflict (Rivers & Stoneman, 2003), which may result in the children re-enacting the conflict in the sibling relationships (Nixon & Cummings, 1999). Siblings may also experience lower self-esteem and higher rates of depression, (Gold, 1993; Rivers & Stoneman, 2003; Rodrigue, Morgan, & Geffken, 1990), which may be related to differential parental treatment, communication difficulties, social interaction and reciprocity deficits, as well as unusual behaviours (Karst & Van Hecke, 2012). Sibling relationships, even when reported to be positive at a young age, tend to deteriorate over time (Rivers & Stoneman, 2003), which may be a result of feelings of anger, jealousy, embarrassment, neglect, or guilt about having negative feelings towards their sibling (Hamilton, 2000).

In addition to psychological and internal consequences, families with a child with ASD manage practical stressors related to waitlists, money, support systems and services, education, access to care, activism, disruption of daily routines, and the large amount of appointments and professionals necessary for supporting their child (Lord & Bishop, 2010; Morrison, Sansosti, & Hadley, 2009; Pakenham, Samios, & Sofronoff, 2005; Woodgate, Ateah, & Secco, 2008). These influences are even more serious when one considers Gabriels, Hill, Pierce, Rogers, and Wehner's (2001) finding that stressors typically found in families with ASD may be exacerbated in families with a low socio-economic status. Hobbies and leisure activities are a common way for adults to manage the negative outcomes of stressful life circumstances, but caregivers and older siblings of children with ASD have significantly less time to devote to enjoyable activities, which increases the negative influence of stressors (Smith et al., 2010). All of these factors influence the family quality of life, which has been found to be significantly lower in families with children with ASD (Lee, Harrington, Louie, & Newschaffer, 2008).

Finally, conflict has shown to be more predictive of ASD symptomatology than positive peer and family relationships, suggesting that children with ASD, although having lower levels of social awareness, are negatively influenced by conflict in the home (Kelly et al., 2008). Negative consequences of family conflict, such as divorce, are higher in families with a child with ASD, presumably because of the increased stress and unexpected demands placed on caregivers (Freedman, Kalb, Zaboltsky, & Stuart, 2012). Caregivers who remain married, on the other hand, report decreased marital satisfaction compared to caregivers of typically developing children (Brobst, Clopton, & Hedrick, 2009; Gau et al., 2011), which also reportedly effects the sibling relationship between children with ASD and typically developing children (Rivers & Stoneman, 2003). Given the common deficits children with ASD experience and the subsequent difficulties the families and caregivers of these children need to face, understanding the protective factors that help families to thrive during this difficult transition is essential.

The foundational work presented in the preceding paragraphs outlining the challenges and negative factors present in families with a child with ASD is valuable and is necessary for professionals to adequately support families with a child with ASD. Nevertheless, as those from a positive psychology perspective would argue, having a balance between the negative, deficit-oriented research and the positive, strengths-oriented research is needed. Particularly, an investigation into the positive emotions, resilience, and ultimately life satisfaction of those with ASD.

Positive Emotions, Life Satisfaction, and Resilience

First, it is necessary to define the terms presented in this section, so as to maintain consistency and clarity in construct application. The subjective nature of both positive emotions and life satisfaction makes them challenging to define in a concise and comprehensive way. Each construct can contain multiple different factors and domains depending on the subjective experience of the individual. Taking a more global approach to these two constructs may be necessary for the purpose of this discussion. Someone asked, “is this experience positive or negative” and “are you satisfied with your life” should be able to provide a response to the question. Therefore, for the purpose of this paper, positive emotions, as outlined by Fredrickson (1998), are emotions such as happiness, curiosity, pleasure, and love and are central to enriching the quality of people’s lives (Diener & Larsen, 1993; Myers & Diener, 1995). And, life satisfaction, as described by Cummins (1996), included the evaluation of seven domains (material well-being, health, productivity, intimacy, safety, community, and emotional well-being) and, more globally, includes the belief that life is close to ideal, conditions of life are excellent, feeling satisfied with life, and getting the important things in life (Diener, Emmons, Larsen, & Griffin, 1985). Although there are several definitions available, most include two specific and necessary components for resilience: (1) the exposure to a significant stressor or stressors; and (2) positive adaptation and response to the stressor (Cicchetti, 2010; Luthar, Sawyer, & Brown, 2006; Rutter, 2012).

In 2009, Cohn, Fredrickson, Brown, Mikels, and Conway connected positive emotions, specifically happiness, with resilience using the broaden-and-build theory. They found that those who experience frequent positive emotions built internal resources and resilience, which allowed them to handle the multitude of challenges they faced. Further, Cohn et al. found that with increased resilience there was increased life satisfaction. If this is true for neuro-typical individuals, can the same be said for individuals with ASD? Can it be applied to families of individuals with ASD?

Both positive emotions and resilience are well-established in the literature as serving an adaptive function in the presence of stress (Charney, 2004; Folkman & Lazarus, 1985; Frijda, 1988; Levenson, 1988). Positive emotions and psychological resilience protect the individual from stress reactivity and promote stress recovery (Ong, Bergeman, Bisconti, & Wallace, 2006). Further, both positive emotions and resilience have been demonstrated to contribute to life satisfaction and success (Cohn et al., 2009; Fredrickson, Cohn, Coffey, Pek, & Finkel, 2008; Lyubomirsky, King, & Diener, 2005). Positive emotions are often thought of as the consequence of successes, which certainly is true; however, happiness contributes significantly and precedes the experience of success in one's life (Lyubomirsky et al., 2005).

Ultimately, it is the moment-by-moment experiences of positive emotions that facilitate the development of growth, new resources, and resilience. When resilience is experienced, it is more predictive of life satisfaction than the acquisition of material wealth and success (Cohn et al., 2009). As such, it can be argued that individuals – such as those with ASD – who have practical barriers to material wealth and success can still experience a high degree of life satisfaction through the generation of positive emotions which, in turn, promote resilience to thrive in adverse circumstances.

As presented above, families with children with ASD experience a wide range of stressors and negative emotions. One might assume that the presence of negative emotions may overwhelm the impact of positive emotions. In fact, the opposite appears to be true: positive emotions predict resilience promotion and life satisfaction even in the presence of negative emotions (Cohn et al., 2009). Individuals with mental health concerns (i.e., depression) or extremely strong negative emotions may need to work to relieve them, but evidence shows that the deliberate activation of positive emotions can still be of benefit (Seligman, Rashid, & Parks, 2006). The implication of this research is invaluable. If the above findings can be proven to be true for individuals with ASD and their families, then the focus of professional intervention can shift to include not only diminishing and mitigating negative experiences and stressors but also the promotion of experiences that generate positive emotions as a way of building and growing resources and resilience.

ASD Resilience

The identification and utility of protective factors and resilience in the presence of ASD has been widely research and is a well-known important factor when working with families with ASD. To date, the majority of resilience research related to ASD has focused on protective factors already present and experienced by caregivers and family members that are used to promote resilience during adverse experiences (Bayat, 2007). Because of the unique experiences that families with members with ASD face, their risk factors and protective factors are unique to them (Bekhet, Johnson, & Zauszniewski, 2012b). Specifically, quality social support from family, friends, professionals, and the community has been discussed in the literature to improve caregiver's resilience (Brobst et al., 2009; Carter, Martinez-Pedraza, & Gray, 2009; Ekas, Lickenbrock, & Whitman, 2010; Hall & Graff, 2011; Tobing & Glenwick, 2007). Another protective factor that has been identified as increasing resilience is a caregiver's locus of control. Siman-Tov and Kaniel (2011) found that when family members had an internal locus of control

– a greater sense of control over their own lives – they were better equipped to manage the stress associated with raising a child with ASD. Similarly, caregivers who were able to engage in cognitive reappraisal of stressful situations were identified as being more resilient (Bayat, 2007; Terry & Hynes, 1998). Cognitive reappraisal coping strategies includes reinterpretation, meaning making, using positive cognitions, and humour, and allowed caregivers to modify the way they understood and thought about stressful events and circumstances (Bekhet, Johnson, & Zauszniewski, 2012a). Finally, hope and optimism – key components of resilience – were found to be fostered through religious beliefs and/or spirituality (Ekas, Whitman, & Shivers, 2009; Luong, Yoder, & Canham, 2009).

Specific investigations into the experience of resilience in individuals with ASD is limited (McCrimmon, Matchullis, & Altomare, 2016). In 2014, McCrimmon and Montgomery provided a list of commonly identified ASD risk factors and suggested ways in which these factors could be also viewed from a resilience-lens (i.e., risk factor: inflexibility – strength: great with structure and routine; risk factor: uneven cognitive skills – strength: areas of marked strength). At the time, there was very little research being done in the area of protective factors or resilience in this population. They felt that by changing the theoretical framework through which we view individuals with ASD and their weaknesses or strengths, the professional community may be better able to promote more balance between deficit-management and strength-enhancement.

Some of the previous literature evaluating other neurodevelopmental disorders has identified symptom severity, duration/course, degree of impairment, functional abilities, and comorbidity as having a significant impact on outcome indicators (Curry et al., 2011; Hinshaw & Lee, 2003), which may provide indications for the importance of resilience in developmental trajectories (McCrimmon et al., 2016). Preliminary investigations into the application of this knowledge to resilience in individuals with ASD has identified the importance of both interpersonal and intrapersonal emotions recognition or emotional intelligence in enhancing resilience through feelings of mastery and a sense of relatedness (McCrimmon et al., 2016) and that deficiencies in emotional intelligence do not emerge until adolescence (Montgomery, Stoesz, & McCrimmon, 2013). As such, the use of emotion-based educational strategies early in the development of individuals with ASD can enhance their resilience and make them better equipped to handle stressful situations later in life (McCrimmon, Climie, & Huynh, 2018). By enhancing children’s emotional intelligence early in life, they will likely be better able to intentionally identify, recall, and utilize positive emotions effectively.

Positive Emotions and ASD

The majority of emotion-focused ASD research identified focuses on the expression and recognition of emotions (e.g., Capps, Yirmiya, & Sigman, 1992; Castelli, 2005; Uljarevic & Hamilton, 2013), and on the experience of negative emotions (i.e., fear, anxiety, depression) in individuals with ASD (e.g., Bruggink, Huisman, Vuijk, Kraaij, & Garnsefski, 2016; Rieffe, Terwogt, & Kotronopoulou, 2007; Uljarević & Evans, 2017), rather than the experience of positive emotions and the resulting positive consequences. Nevertheless, there is a small body of literature that has attempted to take a balanced look at both the recognition of and expression of positive and negative emotions. Shalom et al (2006) concluded that individuals with ASD have the same physiological responses to positive emotions as neurotypical individuals, which implies that difficulty in naming positive emotions may be a result of perception rather than physiological response.

Further, Rieffe et al. (2007) addressed the generally accepted belief that individuals with ASD have significant alexithymia. Their findings did not refute this conclusion, but rather clarified that individuals with ASD are able to differentiate between opposite emotions (the experiences of positive and negative emotions elicited as a result of a single scenario) better than they are able to differentiate between two emotions found on the same end of the spectrum (two negative emotions) and that their inability to differentiate did not impair their awareness of the intensity of the emotion. From the results of Rieffe and colleague's 2007 study, one can conclude that individuals with ASD can identify positive emotions and they have the ability to intentionally recall, focus on, and use positive emotions when asked to do so.

In relation to emotional expression and experience within the family, Williams and Happé (2010) found that all children, including those with ASD, were better able to identify non-social emotions (e.g., happiness) than social emotions (e.g., embarrassment) in others and better able to recall their own personal experiences with non-social emotions than social emotions. These findings can inform the kinds of positive emotions that ought to be focused on in individuals with ASD and their families. Social positive emotions, such as humour, are more difficult to recognize and benefit from for individuals with ASD (Samson & Antonelli, 2013). Therefore, by focusing on non-social positive emotions, individuals with ASD will be better equipped to identify and focus on their positive emotion experiences in order to build their own internal resources. By continuing to explore the experience, promotion, and utility of positive emotions in individuals with ASD and their families, professionals will have another tool available for building resources in these families.

ASD Life Satisfaction

Now that the importance of resilience and positive emotions in individuals with ASD and their families has been argued, further discussion of the implications for life satisfaction is warranted. The use of protective factors to increase resilience has been demonstrated to improve experiences of self-efficacy, acceptance, coherence, optimism, positive family functioning, and enrichment (Bekhet et al., 2012b). Additionally, resilience results in improved parental mental health, better marital quality, better psychological well-being and, ultimately, increased quality of life in family members of individuals with ASD (Carter et al., 2009; Ekas et al., 2010; Kuhn & Carter, 2006; Siman-Tov & Kaniel, 2011; Tobing & Glenwick, 2007; Van Breda, 2001). Resilience promotes these positive outcomes consistently in caregivers and family members and are arguably components of life satisfaction for these families. One of the most established contributors to life satisfaction in caregivers is the role of quality social support (Ekas et al., 2010). At times, however, this protective factor may be outside of the control of the individual or may be difficult to influence depending on circumstance. Identifying intrapersonal protective factors, such as spirituality, internal locus of control, positive cognitions, and positive emotions (Cohn et al., 2009; Luong et al., 2009; Siman-Tov & Kaniel, 2011; Terry & Hynes, 1998), as well as interpersonal protective factors allows caregivers and family members of individuals with ASD to have more control over their own resource building, resilience, and life satisfaction.

Life satisfaction research for individuals with intellectual disabilities has focused on interpersonal success (i.e., social support and interpersonal skills; Miller & Chan, 2008) rather than qualitative experience of life satisfaction. Although this may be due to difficulties in measuring subjective experiences with this population, it should not be assumed that material and interpersonal success are the only avenues through which life satisfaction is experienced.

Intrapersonal quality of life factors may include feelings of autonomy, connectedness, and hope (Burgess & Gutstein, 2007). These factors are clearly and directly related to resilience. When an individual with ASD has a sense of control over choice, feels connected to a support network, and has hope for the future, he or she is better equipped to handle stressful and adverse situations.

Conclusion

Individuals with ASD and their families face untold stressors and challenges that challenge their resilience and ability to thrive. Although identification and remediation of stressors is important, some challenges cannot be avoided. In those cases, these families draw on personal strengths, resources, and resilience to cope. By shifting the ASD program of research towards the examination of personal strengths, the role personal strengths play in promoting resilience, and the impact of those experiences on the full life fulfillment of individuals with ASD and their families, a more balanced understanding of ASD can be procured. Ongoing research investigating the promotion of resilience through internal strengths and resources is sorely needed. This invaluable research can then inform a strength-based, positive and balanced understanding of this population. Individuals with ASD possess strengths of character, unique skills, and untapped resources that should not be undervalued or unappreciated. The professional discussion of these qualities communicates a belief that individuals with ASD and their families can do more than simply survive, they can thrive. They can live enriched and fulfilling lives and they can be valued for what they can offer to society.

References

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Baxter, C., Cummins, R., & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual and Developmental Disability, 25*, 105-118. doi: 10.1080/13269780050033526

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*, 702-714. doi: 10.1111/j.1365-2788.2007.00960.x

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012a). Effects on resilience of caregivers of persons with autism spectrum disorder: The role of positive cognitions. *Journal of the American Psychiatric Nurses Association, 18*, 337-344. doi: 10.1177/10788390312467056

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012b). Resilience in family members of persons with autism spectrum disorder: A review of the literature. *Issues in Mental Health Nursing, 33*, 650-656. doi: 10.3109/01612840.2012.671441

Bornstein, M. H. (2001). Parenting: Science and practice. *Parenting: Science and Practice, 1*, 1-4. doi: 10.1080/15295192.2001.9681208

Brobst, J. B., Clopton, J. R., & Hedrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24*, 38-49. doi: 10.1177/1088357608322699

Broderick, C. B. (1995). Understanding family process: Basics of family systems theory. Thousand Oaks, CA: Sage Publications.

Bruggink, A., Huisman, S., Vuijk, R., Kraaij, V., & Garnsefski, N. (2016). Cognitive emotion regulation, anxiety and depression in adults with autism spectrum disorder. *Research in Autism Spectrum Disorders, 22,* 34-44. http://dx.doi.org/10.1016/j.rasd.2015.11.003

Burgess, A. F., & Gutstein, S. E. (2007). Quality of life for people with autism: Raising the standard for evaluating successful outcomes. *Child and Adolescent Mental Health, 12*, 80-86. doi: 10.1111/j.1475-3588.2006.00432.x

Capps, L., Nirmiya, N., & Sigman, M. (1992). Understanding of simply and complex emotions in non-retarded children with autism. *Journal of Child Psychology and Psychiatry, 33*, 1169-1182. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.1469-7610.1992.tb00936.x

Carter, A. S., Martinez-Pedraza, F. D. L., & Gray, S. A. O. (2009). Stability and individual change in depressive symptoms among mothers raising young children with ASD: Maternal and child correlates. *Journal of Clinical Psychology, 65*, 1270-1280. doi: 10.1002/jclp.20634

Castelli, F. (2005). Understanding emotions from standardized facial expressions in autism and normal development. *Autism, 9*, 428-449. https://doi-org.login.ezproxy.library.ualberta.ca/10.1177/1362361305056082

Centers for Disease Control and Prevention. (2014). *Autism spectrum disorder (ASD)*. Retrieved from http://www.cdc.gov/ncbddd/autism/data.html

Charney, D. S. (2004). Psychobiological mechanisms of resilience and vulnerability: Implications for successful adaptation to extreme stress. *American Journal of Psychiatry, 161*, 195-216. https://doi.org/10.1176/foc.2.3.368

Cicchetti, D. (2010). Resilience under conditions of extreme stress: A multilevel perspective. *World Psychiatry, 9*, 145-154. https://doi-org.login.ezproxy.library.ualberta.ca/10.1002/j.2051-5545.2010.tb00297.x

Cicchetti, D., & Toth, S. L. (1998). The development of depression in children and adolescents. *American Psychologist, 53*(2)*,* 221-241.

Cohn, M. A., Fredrickson, B. L., Brown, S. L., Mikels, J. A., & Conway, A. M. (2009). Happiness unpacked: Positive emotions increase life satisfaction by building resilience. *Emotion, 9*, 361-368. doi: 10.1037/a0015952

Coleman, M. (1989). Young children with autism or autistic-like behavior. *Infants and Young Children, 1*, 22-31.

Combrinck-Graham, L. (1990). Developments in family systems theory and research. *Journal of the American Academy of Child and Adolescent Psychiatry, 29*, 501-512. doi: 10.1097/00004583-199007000-00001

Cummins, R. A. (1996). The domains of life satisfaction: An attempt to order chaos. *Social Indicators Research, 38*, 303-328. https://doi-org.login.ezproxy.library.ualberta.ca/10.1007/BF00292050

Curry, J., Silva, S., Rohde, P., Ginsburg, G., Kratochvil, C., Simons, A., … March, J. (2011). Recovery and recurrence following treatment for adolescent major depression. *Archives of General Psychiatry, 68*, 263-269. doi:10.1001/archgenpsychiatry.2010.150

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment, 49,* 71-75. 10.1207/ s15327752jpa4901_13

Diener, E., & Larsen, R. J. (1993). The experience of emotional well-being. In M. Lewis & J. M. Haviland (Eds.), *Handbook of emotions* (pp. 405-415). New York, NY: Guildford Press.

Doron, H., & Sharabany, A. (2013). Marital patterns among parents to autistic children. *Psychology, 4*, 445-453. doi: 10.4236/psych.2013.44063

Duckworth, A. L., Steen, T. A., & Seligman, M. E. P. (2005). Positive psychology in clinical practice. *Annual Review of Clinical Psychology, 1*, 629-651. doi: 10.1146/annurev.clinpsy.1.102803.144154

Dyson, L. L. (2003). Children with learning disabilities within the family context: A comparison with siblings in global self-concept, academic self-perception, and social competence. *Learning Disabilities Research & Practice, 18*, 1-9. doi:10.1111/1540-5826.00053

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 1274-1284. doi: 10.1007/s10803-010-0986.y

Ekas, N. V., Whitman, T. L., & Shivers, C. (2009). Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 39*, 706-719. doi: 10.1007/s10803-008-0673-4

Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology, 48*, 150-170.

Fredrickson, B. L. (1998). What good are positive emotions? *Review of General Psychology, 2*, 300-319.

Fredrickson, B. L., Cohn, M. A., Coffey, K. A., Pek, J., Finkel, S. M. (2008). Open hearts build lives: Positive emotions, induced through loving-kindness meditation, build consequential personal resources. *Journal of Personality and Social Psychology, 95,* 1045-1062. doi: 10.1037/a0013262

Freedman, B. H., Kalb, L. G., Zaboltsky, B., & Stuart, E. A. (2012). Relationship status among parents of children with autism spectrum disorders: A population-based study. *Journal of Autism and Developmental Disorders, 42*, 539-548. doi: 10.1007/s10803-011-1269-y

Frijda, N. H. (1988). The laws of emotion. *American Psychologist, 43*, 349-358.

Gabriels, R. L., Hill, D. E., Pierce, R. A., Rogers, S. J., & Wehner, B. (2001). Predictors of treatment outcome in young children with autism: A retrospective study. *Autism, 5*, 407-429. doi: 10.1177/1362361301005004006

Gau, S. S., Chou, M., Chiang, H., Lee, J., Wong, C., Chou, W., & Wu, Y. (2011). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders, 6*, 263-270. doi: 10.1016/j.rasd.2011.05.007

Glass, P. W. (2001). *Autism and the family: A qualitative perspective* (Doctoral dissertation, Virginia Polytechnic Institute and State University). Retrieved from http://www.researchgate.net/profile/Marilyn_Lichtman/publication/253191008_AUTISM_AND_THE_FAMILY_A_QUALITATIVE_PERSPECTIVE/links/02e7e52a758983b89c000000.pdf

Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders, 23*, 147-163. doi: 10.1007/BF01066424

Hall, H. R. & Graff, J. C. (2011). The relationships among adaptive behaviours of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing, 34*, 4-25. doi: 10.31109/0146-862.2011.555270

Hamilton, L. (2000). *Facing autism: Giving parents reasons for hope and guidance for help.* Colorado Springs, CO: Water Brook Press.

Hinde, R. A., & Stevenson-Hinde, J. (1987). Interpersonal relationships and child development. *Developmental Review, 7*, 1-21. doi:10.1016/0273-2297(87)90002-5

Hinshaw, S. P., & Lee, S. S. (2003). Conduct and oppositional defiant disorders. In E. J. Mash & R. A. Barkley (Eds.), *Child psychopathology (2nd ed.)*. New York, NY: Guildford Press.

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*, 217-250.

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of Autism Spectrum Disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychological Review, 15*, 247-277. doi: 10.1007/s10567-012-0119-6

Kelly, A. B., Garnett, M. S., Attwood, T., & Peterson, C. (2008). Autism spectrum symptomatology in children: The impact of family and peer relationships. *Journal of Abnormal Child Psychology, 36*, 1069-1081. doi: 10.1007/s10802-008-9234-8

Kuhn, J. C., & Carter, A. S., (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry, 76*, 564-575. doi: 10.1037/0002-9432.76.4.564

Lee, L., Harrington, R. A., Louie, B. B., & Newschaffer, C. J. (2008). Children with autism: Quality of life and parental concerns. *Journal of Autism and Developmental Disorders, 38*, 1147-1160. doi: 10.1007/s10803-007-0491-0

Levenson, R. W. (1988). Emotion and the autonomic nervous system: A prospectus for research on autonomic specificity. In H. L. Wagner (Ed.), *Social psychophysiology and emotion: Theory and clinical applications* (pp. 17-42). Oxford, England: Wiley.

Lord, C., & Bishop, S. L. (2010). Autism spectrum disorders: Diagnosis, prevalence, and services for children and families. *Society for Research in Child Development, 24*, 1-21.

Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast Asian parents raising a child with autism: A qualitative investigation of coping styles. *Journal of School Nursing, 25*, 222-229. doi: 10.1177/1059840509334365

Luthar, S. S., Sawyer, J. A., & Brown, P. J. (2006). Conceptual issues in studies of resilience: Past, present, and future research. *Annals of the New York Academy of Sciences, 1094*, 105-115. doi: 10.1196/annals.1376.009

Lyubomirsky, S., King, L., & Diener, E. (2005). The benefits of frequent positive affect: Does happiness lead to success? *Psychological Bulletin, 131*, 803-855. doi: 10.1037/0033-2909.131.6.803

Maccoby, E. E., & Martin, J. A. (1983). Socialization in the context of the family: Parent-child interaction. In E. M. Hetherington (Ed.) and P. H. Mussen (Series Ed.), *Handbook of Child Psychology, (vol. 4), Socialization, personality and social development* (pp. 1-101). New York: Wiley.

Maddux, J. E. (2002). Stopping the 'madness': Positive psychology and the deconstruction of the illness ideology and the DSM. In C. Snyder & S. J. Lopez (Eds.), *Handbook of positive psychology* (pp. 13-25). New York: Oxford University Press.

Maddux. J. E., Gosselin, J. T., & Winstead, B. A. (2005). Conceptions of psychopathology: A social constructionist perspective. In J. E. Maddux & B. A. Winstead (Eds.), *Psychopathology: Foundations for a contemporary understanding* (pp. 3-18). New York: Lawrence Erlbaum Associates.

Maddux, J. E., Snyder, C. R., & Lopez, S. J. (2004). Toward a positive clinical psychology: Deconstructing the illness ideology and constructing an ideology of human strengths and potential. In P. A. Linley & S. Joseph (Eds.), *Positive psychology in practice* (pp. 320-334). Hoboken, NJ: John Wiley & Sons Inc.

McCrimmon, A. W., Matchullis, R. L., & Altomare, A. A. (2016). Resilience and emotional intelligence in children with high-functioning autism spectrum disorder. *Developmental Neurorehabilitation, 19*, 154-161. doi: 10.3109/17518423.2014.927017

McCrimmon, A. W., Climie, E. A., & Huynh, S. (2018). The relation between emotional intelligence and resilience in at-risk populations. *Developmental Neurorehabilitation, 21*, 326-335. doi: 10.1080/17518423.2017.1387873

McCrimmon, A. W., & Montgomery, J. M. (2014). Resilience-based perspectives for autism spectrum disorder. In S. Prince-Embury & D. Saklofske (eds.), *Resilience Interventions for Youth in Diverse Populations. The Springer Series on Human Exceptionality.* New York, NY: Springer. https://doi-org.login.ezproxy.library.ualberta.ca/10.1007/978-1-4939-0542-3_17

Miller, S. M., & Chan, F. (2008). Predictors of life satisfaction in individuals with intellectual disabilities. *Journal of Intellectual Disability Research, 52*, 1039-1047. doi: 10.1111/j.1365-2788.2008.01106.x

Montgomery, J. M., Stoesz, B. M., & McCrimmon, A. W. (2013). Emotional intelligence, theory of mind, and executive functions as predictors of social outcomes in young adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities, 28*, 4-13. doi: 10.1177/10883576124615

Morrison, J. Q., Sansosti, F. J., & Hadley, W. M. (2009). Parent perceptions of the anticipated needs and expectations for support for their college-bound students with Asperger's syndrome. *Journal of Postsecondary Education and Disability, 22*, 78-87.

Myers, D. G., & Diener, E. (1995). Who is happy? *Psychological Science, 6*, 10-19.

Nixon, C. L., & Cummings, E. M. (1999). Sibling disability and children's reactivity to conflicts involving family members. *Journal of Family Psychology, 13*, 274-285.

Norton, P. & Drew, C. (1994). Autism and potential family stressors. *The American Journal of Family Therapy, 22*, 67-76. doi: 10.1080/01926189408251298

Ong, A. D., Bergeman, C. S., Bisconti, T. L., & Wallace, K. A. (2006). Psychological resilience, positive emotions, and successful adaptation to stress in later life. *Journal of Personality and Social Psychology, 91*, 730-749. doi: 10. 1037/0022-3514.91.4.730

Padilla-Walker, L. M., Harper, J. M., & Jensen, A. C. (2010). Self-Regulation as a mediator between sibling relationship quality and early adolescents' positive and negative outcomes. *Journal of Family Psychology, 24*, 419-428. doi: 10.1037/a0020387

Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment. *Autism, 9*, 181-212. doi: 10.1177/1362361305049033

Pottie, C. G., & Ingram, K. M. (2008). Daily stress, coping, and well-being in parents of children with autism: A multilevel modeling approach. *Journal of Family Psychology, 22*, 855-864. doi: 10.1037/a0013604

Pulg, A., Koro-Ljungberg, M., & Echevarrla-Doan, S. (2008). Social constructionist family systems research: Conceptual considerations. *The Family Journal: Counseling and Therapy for Couples and Families, 16*, 139-146. doi: 10.1177/1066480707313785

Radke-Yarrow, M. (1999). *Children of depressed mothers: From early childhood to maturity.* Cambridge, UK: Cambridge University Press.

Rieffe, C., Terwogt, M. M., & Kotronopoulou, K. (2007). Awareness of single and multiple emotions in high-functioning children with autism. *Journal of Autism and Developmental Disorders, 37,* 455-465. doi: 10.1007/s10803-006-0171-5

Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders, 33*, 383-394. doi: 10.1023/A:1025006727395

Rodrigue, J. R., Morgan, S. B., & Geffken, G. R. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology, 19*, 371-379. doi: 10.1207/s15374424jccp1904_9

Rutter, M. (1979). Maternal deprivation, 1972-1978: New findings, new concepts, new approaches. *Child Development, 50*, 283-305.

Rutter, M. L. (2011). Progress in understanding autism: 2007-2010. *Journal of Autism and Developmental Disorders, 41*, 395-404. doi: 10.1007/s10803-011-1184-2

Rutter, M. L. (2012). Resilience as a dynamic concept. *Development and Psychopathology, 24*, 335-344. doi: 10.1017/ S0954579412000028

Samson, A. C., & Antonelli, Y. (2013). Humor as character strength and its relation to life satisfaction and happiness in Autism Spectrum Disorders. *International Journal of Humor Research, 26,* 477-491. https://doi.org/10.1515/humor-2013-0031

Sanua, V. D. (1986). A comparative study of opinions of U.S.A. and European professionals on the etiology of infantile autism. *The International Journal of Social Psychiatry, 32*, 16-30.

Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *The American Psychologist, 55*, 5-14. doi: 10.1037/003-066X.55.1.5

Seligman, M. E. P., Rashid, T., & Parks, A. C. (2006). Positive psychotherapy. *American Psychologist, 61*(8), 774-788.

Shalom, D. B., Mostofsky, S. H., Hazlett, R. L., Goldberg, M. C., Landa, R. J., Faran, Y., McLeod, D. R., & Hoehn-Saric, R. (2006). Normal physiological emotions but differences in expression of conscious feelings in children with high-functioning autism. *Journal of Autism and Developmental Disorders, 36*, 395-400. doi: 10.1007/s10803-006-0077-2

Siman-Tov, A. & Kaniel, S. (2011). Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model. *Journal of Autism and Developmental Disorders, 41*, 879-890. doi: 10.1007/s10803-010-112-x

Smith, M. (2011). Measures for assessing parenting in research and practice. *Child and Adolescent Mental Health, 16*, 158-166. doi:10.1111/j.1475-3588.2013.00585.x

Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 167-178. doi: 10.1007/s10803-009-0844-y

Sroufe, L. A., Carlson, E. A., Levy, A. K., & Egeland, B. (1999). Implication of attachment theory for developmental psychopathology. *Development and Psychopathology, 11*, 1-13.

Terry, D. & Hynes, G. (1998). Adjustment to a low-control situation: Reexamining the role of coping responses. *Journal of Personality and Social Psychology, 74*, 1078-1092. doi: 10.1037/0022-3514.74.4.1078

Tobing, L. E. & Glenwick, D. S. (2007). Predictors and moderators of psychological distress in mothers of children with pervasive development disorders. *Journal of Family Social Work, 10*, 1-22. doi: 10.1300/J039v10n04_01

Uljarević, M., & Evans, D. W. (2017). Relationship between repetitive behaviour and fear across normative development, autism spectrum disorder, and down syndrome. *Autism Research, 10*, 502-507. https://doi-org.login.ezproxy.library.ualberta.ca/10.1002/aur.1674

Uljarević, M., & Hamilton, A. (2013). Recognition of emotions in autism: A formal meta-analysis. *Journal of Autism and Developmental Disorders, 43*, 1517-1526. doi: 10.1007/s10803-012-1695-5

Van Breda, A. D. (2001). *Resilience theory: A literature review.* Pretoria, South Africa: South African Military Health Service.

Volkmar, F. R., & Pauls, D. (2003). Autism. *The Lancet, 362*, 1133-1141. http://dx.doi.org/10.1016/S0140-6736(03)14471-6

Williams, D., & Happé, F. (2010). Recognising 'social' and 'non-social' emotions in self and others: A study of autism. *Autism, 14*, 285-304. https://doi-org.login.ezproxy.library.ualberta.ca/10.1177/1362361309344849

Wood, A. M., & Tarrier, N. (2010). Positive clinical psychology: A new vision and strategy for integrated research and practice. *Clinical Psychology Review, 30*, 819-829. doi: 10.1016/j.cpr.2010.06.003

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative Health Research, 18*, 1075-1083. doi: 10.1177/1049732308320112

CHAPTER THREE: Promoting Family Resilience through the ASD Diagnostic Assessment: Part I: Helping and Hindering Factors for Professionals

As with all people, the presence of protective factors, which allow resilience to flourish, is valuable for families with a child with Autism Spectrum Disorder (ASD; Harris & Glasberg, 2003). Although the role of resilience in families with ASD has been fairly widely researched (Bekhet, Johnson, & Zauszniewski, 2012), specific recommendations for facilitating family resilience has not be identified. Without this information, professionals are left with a theoretical understanding of the importance of resilience, but an uncertainty about how to take the theoretical knowledge to the practical implementation. This two-part research report seeks to fill a gap currently found in ASD research. The first paper (Part I) in this two-part series will specifically address the implications of this research for professionals engaging in ASD diagnostic assessments and support of families with a child with ASD. This paper will provide practical and informative suggestions for improving the diagnosis process and system as identified by the families most recently impacted by it. The second paper (Part II) will focus on the role individual families can play in fostering and promoting their own family resilience.

Literature Review

Resilience, and the way caregivers perceive, and experience family resilience deeply impacts the functioning of a family. Walsh (2010) defines family resilience as the ability to face, survive, and learn from adverse experiences. Resilience is an individual's or family's ability to progress through life effectively despite the presence of difficult or unfortunate circumstances (Alvord & Grados, 2005). Additionally, Masten (2001) described resilience as a "class of phenomena characterized by good outcomes in spite of serious threats to adaptation or development" (p. 228). When a child has ASD, the family inevitably deals with adversity, difficulty, and hardships as a result (Bayat, 2007). Many of these families continue to thrive, successfully adapting to their situations, which would classify them as resilient.

In order to better understand how families cope with the known stressors of having a child with ASD, a comprehensive literature review of protective factors and, more specifically, resilience was conducted. The concept of protective factors dates back to as early as the 1980s (Rutter, 1987). According to Rutter, protective factors are “the positive role of individual differences in people’s response to stress and adversity” (p. 316). Resilience is primarily concerned with an individual’s response to adversity. Adversity can cause some people to become overly stressed and worn out, whereas other people overcome and even thrive during these difficult times. Resilience is not necessarily a fixed characteristic, however, and individuals who are resilient during one life event, may not be resilient during the next difficult circumstance (Rutter, 1987). Facing difficulties and trials is one of the most common human experiences. Not all people possess the necessary skills and abilities to cope with the adversity, but those that do are said to be resilient (Masten, 2014). Resilience, however, is not an elusive, characteristic that few can possess. Resilience, as Masten (2014) describes, “arises from ordinary resources and processes” (p. 3). Difficult circumstances give regular people the opportunity to draw upon their positive qualities to be resilient.

The role family’s play in how individuals experience resilience is a fundamental topic of interest at the present time (Masten, 2007). In 1985, Masten and Garmezy identified three factors: (a) personality; (b) family cohesion; and, (c) external support systems, that contribute to an individual’s capacity to face hardship – all of which continue to be relevant today (Li, Godinet, & Arnsberger, 2011; Masten, 2014). The family, depending on overall health, is threatened, vulnerable, or resilient in a similar way to an individual’s development (Becvar, 2013; Patterson, 2002). According to Masten (2014), family competence and family resilience are interconnected. A competent family has been described as “responsive, open, and flexible; connected to the community; active in problem solving; and providing age-appropriate autonomy to their children” (Masten, 2014, p. 203; Masten & Obradović, 2006). Additionally, communication is considered to be an important adaptive quality. Therefore, a competent family, when faced with adversity, will be flexible while maintaining effective communication and closeness. As families develop and mature, the roles, rules, and routines adapt to meet the changing needs of the family. These routines are imperative during times of adversity. The more equipped families are to maintain the well-established routines, the more resilient they are when facing difficult circumstances (Fiese, 2006).

To date, family resilience theory has not been clearly articulated within a disabilities program of research. As a result, it is difficult to understand whether family resilience is different than family strengths. Bayat (2007) suggested that the difference between family resilience and family strengths is whether the factors existed prior to the diagnosis of the disability or if they emerged out of the families attempt to manage the disability. As such, the fostering of family resilience can and will occur most optimally during the diagnostic assessment process, when and if professionals have the necessary know-how to do so.

Resilience during ASD Diagnostic Assessment

Caregivers’ of newly diagnosed children with ASD are often left in shock, disbelief, and uncertainty (Evans, 2010). The task of helping their family cope with the significant consequences of their situation is stressful and difficult (Glass, 2001). Resilience is an extremely important factor to the success of families with children with ASD. Fostering resilience should begin immediately after a diagnosis of ASD has been given to families.

Having a child diagnosed with ASD has significant impact at an individual/personal level of functioning, the stress and decision-making regarding how to proceed in supporting the child is at the family level of functioning, and advocacy and stigma management is at the community level of functioning (as cited in Patterson, 2002). The family balances these demands with its abilities, such as, caregiver support, education, community resources, extended family assistance, and financial support. Families then proceed to making meaning out of their demands and abilities, their family identity, and their personal worldview and philosophy. By making meaning (or not making meaning) families are defining the extent to which the risk and/or protective abilities influence their family. Families then adjust their beliefs and worldview to make sense of the new diagnosis of ASD and to adapt to the new trajectory their family is on (Patterson, 2002).

Zand, Braddock, Baig, Deasy, and Maxim (2013) acknowledge the important role professionals play in the above process and in facilitating resilience in caregivers of children with ASD. They argue that by providing the necessary support, caregivers are more likely to follow through with specific treatment plans, intervention strategies, and follow up appointments. Psychologists conducting diagnostic assessments could be considered the frontline workers in facilitating caregiver resilience in the presence of ASD. Encouraging caregiver self-efficacy, self-sufficiency, self-management, personal agency, and problem solving are excellent first steps (Mazzucchelli & Sanders, 2012). Providing a family friendly environment that allows space for caregivers to make decisions is an effective way to promote caregiver resilience (Zand et al., 2013).

A systematic review of the literature yielded no empirical measure of resilience in response to ASD diagnostic assessment. To date, there are no specific tools for the facilitation of resilience during the ASD diagnostic assessment, but there is evidence that therapeutic assessment can play a valuable role in promoting resilience (Finn & Tonsager, 1992; Tharinger et al., 2009). Additionally, the strategies provided by Zand and colleagues (2013) have little empirical support and are suggested by professionals rather than allowing actual caregiver responses to inform practice. This gap in the literature suggests that new research needs to consider the role of the diagnostic assessment in setting caregivers up for positive outcomes. Allowing caregivers to communicate their experiences and educate psychologists regarding helpful techniques and practices can be a rewarding experience. As a result, families of children with ASD will have the opportunity to begin their parenting-journey full of optimism and resilience.

My primary objective, in conducting this study, is to better understand how families with children with ASD can be assisted to capitalize on their strengths. A lack of resilience in caregivers may make it difficult for the caregiver to remain engaged with and supportive of his/her child with ASD (Truitt, Biesecker, Capone, Bailey, & Erby, 2012). It is well known that problems in the home spread outward and affect many levels of one's social infrastructure. Disengaged parenting has been linked to increased stress levels, disruptive behaviours, and emotional dysregulation in children in the classroom (Masten et al., 1988). Children without adequate support at home display greater need (through emotional and behavioural problems) within the educational system; placing further demands on teachers and educational professionals (Avramidis, Bayliss, & Burden, 2000). If the child without adequate support at home also has a special need (such as ASD) one might assume the burden would be substantially worse. As a result, these children may leave their educational institution without having received the expected skills. Therefore, when a child's emotional needs are being met at home, the child is better equipped to be a positively contributing member of the classroom environment, leading to success in future endeavours.

Using a qualitative research inquiry to address this gap serves three purposes. First, it creates a knowledge base about the factors that promote resilience through the ASD diagnostic assessment; factors that can later be evaluated quantitatively through larger scale projects or intervention studies. Second, parents and caregivers are given the opportunity to provide valuable feedback about resilience-promoting or harming experiences during the ASD diagnostic assessment. Third, it encourages diagnosticians and diagnostic teams to consider their families' experiences, preferences, emotional needs, and capacities during their work together. This information, primarily intended for professionals, will encourage them to (a) recognize the importance of family resilience and (b) facilitate assessment environments in which family resilience is promoted. Additionally, by providing professionals with this information, they will be better equipped to assist families in becoming as well-functioning as possible. As with all family interactions, positive experiences in a family with a child with ASD will lead to better well-being and a more encouraging future for those involved. Thus, the positive impact of this research will not be limited to professionals and families of children with ASD but will also positively impact the peers of children with ASD, the education system, and society at large.

The Present Study

The primary research question for this study is: What experiences help and hinder a caregiver's or caregivers' perceptions of family resilience during the ASD diagnostic assessment process? This part of the study (Part I) addresses the specific professional experiences of the caregiver participants.

To address the primary research question, specific qualitative research questions were also developed to guide the semi-structured interview process:

- What incidences help caregivers' experiences of family resilience during the ASD diagnostic assessment process?
- What incidences hinder caregivers' experiences of family resilience during the ASD diagnostic assessment process? And,
- What do caregivers believe could have helped their experiences of family resilience during the ASD diagnostic assessment process?

Methodology

The Enhanced Critical Incident Technique (ECIT) as described by Butterfield and her colleagues in 2009 was used to answer the identified research questions. In 1954, Flanagan developed the Critical Incident Technique (CIT) to focus on a critical event, incident, or factor that either helps or hinders the performance or experiences of a specific situation or event (as cited in Butterfield et al., 2009). Butterfield et al. (2009) provided a comprehensive protocol using Flanagan's CIT within the Counselling Psychology field. Butterfield et al.'s adaptation was then dubbed the Enhanced Critical Incident Technique (ECIT).

Recruitment

Because the desired sample is relatively structured, inclusion/exclusion criteria was defined. One of the primary criteria for this study is caregiver perception, thus the participants are all caregivers in a family with at least one child. In addition, the families included at least one child recently (within the year prior to the interview) diagnosed with Autism Spectrum Disorder. Finally, the caregiver participants needed to have been diagnosed in Alberta, Canada.

Participants were recruited through social media websites, doctors' offices, private practices, and public notice boards within Alberta, Canada. Posters, information pamphlets, and letters were distributed throughout Alberta in order to identify individuals who meet the inclusion criteria outlined above. Any participants who volunteer and met the inclusionary criteria for the study were invited to participate in the interview process. A $20 gift card was offered to participants as an incentive for their participation in this study.

Participants

The sample consisted of 12 primary caregivers (12 females; 11 European-Canadians, one Haitian-Canadian; 10 born in Canada and two born in England) between the ages of 27 and 41 who had a child diagnosed within the year preceding the interview in Alberta, Canada. At the time of the interviews, 58% of participants had completed some college education, 33% had university degrees, and 8% had completed high school as their highest level of education. In terms of annual yearly income, 33% of participants stated living within the $51,000 to $70,000 range, 33% within the $91,000 to $110,000 range, 8% within the $71,000 to $90,000 range, 8% within the $111,000 to $130,000 range, 8% in the $171,000+ range, and 8% chose not to disclose income information. Forty-two percent of participants stated they had no religious or spiritual affiliations, 33% identified as Christian, 8% identified as agnostic, 8% as Catholic, and 8% as Latter-Day Saints. Regarding the children recently diagnosed with ASD, 83% were male and 17% were female ranging from three to nine years of age.

Data Collection

Participants were provided a detailed description of the study with the informed consent (Appendix A) prior to scheduling a semi-structured interview, based on the protocols of Enhanced Critical Incident Technique (Butterfield, et al., 2009; Appendix B). Data was collected in-person for all but one participant for whom the interview was completed via telephone. The interviews were audio-recorded and then transcribed prior to analysis. For each interview, participants were invited to provide demographic information, their own personal definition of family resilience, and contextual information about their diagnostic assessment experience. This information was useful in providing a context foundation through which the critical incidents and wish list items could be better understood (Butterfield et al., 2009). Participants were asked the following context building questions: (a) what was the diagnostic process for you and your family? (b) how do you define family resilience? (c) do you believe your family resilience was impacted through the diagnostic process? (d) did you expect the ASD diagnosis? and (e) what was your reaction to receiving the diagnosis? Follow-up questions were asked to maintain the focus on the family's experiences rather than the individual participant's experiences.

Participants were then asked to reflect on how their diagnostic assessment experiences influenced their ability to feel family resilience. Each participant was asked to identify as many specific incidents, events, or factors that were significant in helping their family feel resilient by asking the following questions: "Reflecting on your recent ASD diagnosis appointment, what specifically in that appointment helped you to feel more resilient?" or "What incidences in your diagnosis appointment do you identify as making it more difficult for you to feel resilient?". Participants were also given the opportunity to identify wish list items; that is, things that the participants wished they had experienced in their assessment appointments that they believe would have helped their family feel more resilience. Follow up questions and probes were asked to gain more information regarding the participant's experiences.

All 12 participants were available for participant credibility checks, which were completed by electronically sending each of them a summary of the incidents retrieved from their interview. These summaries were sent after the initial analysis of the data was completed and were used to: (a) confirm the importance of the critical incidents and wish list items, (b) clarify the accuracy of the interpretation of the data, and (c) ensure that the participants' experiences were accurately accounted for by allowing them to review categories into which the incidents and factors were organized.

Data Analysis

Butterfield et al.'s (2009) analysis procedures were followed to analyze the transcript data. First, the raw data was organized into contextual data, helping critical incidents, hindering critical incidents, wish list items, and examples of helping or hindering qualities. The critical incidents (CI) and wish list items (WL) were analyzed first. Each critical incident (both helping and hindering) and wish list item were separated into similar themes and categories. Once the incidents and items were sorted, categories were created to best describe the compiled data.

Category titles were written for each group of identified incidents and items. Credibility checks, as suggested by Butterfield et al. (2009) were conducted in order to ensure that the results accurately reflected the perceptions of the participants. First, the interviews were audiotaped. Second, interview fidelity was maintained by avoiding leading questions or prompting the participants in specific ways. Third, exhaustiveness (ensuring that no new categories are possible after the final interview has been coded) was achieved for the helping categories after the eighth interview, after the seventh interview for the hindering categories, and after the ninth interview for the wish list categories. Fourth, participation rates (the number of participants who identified a specific theme or category) were calculated and categories were considered to be valid if they were identified by at least 25% of the participants. Fifth, an independent judge placed the incidents into categories yielding 100% consistency between the independent evaluator and the researcher. Sixth, cross-checking by participants was completed by electronic review of the incidents and categories. Seventh, an expert in working with families with a child with ASD was consulted and reviewed the findings for usefulness and validity. Finally, theoretical agreement was sought through a thorough review of the literature. It is noteworthy, however, that a lack of theoretical agreement does not necessary indicate poor credibility. Rather, it may suggest the revelation of new and important information (Butterfield et al., 2005; 2009).

Researcher-As-Instrument

Given the qualitative nature of this research, it is necessary and valuable to acknowledge the role of the researcher in the process of understanding the data. Researcher's assumptions, biases, and expectations all influence the way the interviews are conducted, understood, analyzed, and interpreted. Although ECIT creates a structured method designed to increase the research rigour, subjectivity and researcher influence cannot be entirely eliminated.

The author adheres to a positive psychology perspective which ultimate creates the assumption and expectations that everyone is capable of experiencing resilience when given the opportunity and support to do so. Conversely, the opposite is believed to be true; if individuals are in situations that are invalidating and unsupportive, their ability to experience resilience may be challenged. Additionally, the author acknowledges a belief that raising a child with ASD can be a rewarding and enjoyable experience when provided with the necessary tools and resources to do so. These beliefs and perspectives created a lens through which the interviews, data analysis and findings were conducted and understood.

Findings

Participants were asked whether they expected the diagnosis and what their reaction to the diagnosis was: four of the 12 participants reported that they expected the ASD diagnosis; three participants expected a diagnosis of some kind but did not know if it would be ASD; three participants stated they expected the diagnosis, but their husband did not; and, two participants reported not expecting the ASD diagnosis. For four of the participants the diagnosis came as a relief and helped them feel more prepared to move forward with supporting their child. For the remaining eight participants, however, feelings of shock, surprise, grief, guilt, denial, and self-blame accompanied the diagnosis.

When considering the participants' personal definitions of family resilience, four specific constructs were identified. First, all 12 participants described family resilience as the whole family's acceptance of the difficult situation and moving forward with a healthy emotional, mental, and spiritual life together; the ability to "bounce back" after receiving the diagnosis of ASD. Additionally, two participants stated that having family resilience included finding and accessing supports, both emotional supports and practical supports, that would rally around the family. Two other participants stated that they felt family resilience because they were able to fight and advocate for their children. Finally, one participant spoke about her family resilience as their ability to choose to "find something that's gonna – it's gonna teach us, grow us, stretch us, somehow, and make us better."

The 12 participants described a total of 274 helping and hindering critical incidents and wish list items divided into a total of 18 helping categories, 13 hindering categories, and 10 wish list categories. Further, the categories were divided into two groups; factors that are relevant to professionals in the ASD diagnosis field and factors that are relevant for family decision making and navigation of the ASD diagnosis process. Only the factors relevant for professionals will be described in this paper. For information regarding family navigation of the ASD diagnosis process, refer to Part II of this study. For Part I, there were 79 helping CIs organized into 12 categories (Table 1), 36 hindering CIs organized into 7 categories (Table 2), and 52 WLs organized into 8 categories (Table 3). Only CIs and WLs endorsed by at least 25% of participants will be further discussed.

Helping CI Categories

Table 1

Part I: Categories of Critical Incidents that were Perceived to Help Family Resilience

Category	PA	IN	%
Receiving accurate information and/or guidance	10	22	**83**
Feeling supported by assessment team	8	16	**67**
Affirmations and reassurance about parenting	7	8	**58**
Accurate representation and feedback about child's abilities	5	7	**42**
Ease of communication with assessment team	5	5	**42**
Positive and supportive treatment of child	4	5	**33**
Information about what to expect during the assessment process	3	4	**25**
Hope for the future	3	4	**25**
Multidisciplinary assessment team	3	3	**25**
Receiving diagnosis quickly	2	2	17
Organized family mentorship	2	2	17
Time to process information	1	1	8

Note. Participation rate > 25% are in boldface. PA = # of participants (N=12); IN = # of incidents (N=274); % = participation rate percentage.

Receiving accurate information and/or guidance was the helping CI category with the greatest participation rate. It was defined as the receipt of specific, accurate, and timely information and advice from professionals regarding the ASD diagnosis process and/or applying for, accessing, and engaging in ASD-specific supports, services, and resources. The participants reported receiving valuable information in several content areas: a thorough and clear debrief of the assessment report; the family's emotional needs; resources for gaining ASD-specific knowledge; sharing the diagnosis with others, and the necessary steps following the ASD diagnosis. Additionally, one participant talked about the importance of the professionals finding a balance between providing enough information to the family without overwhelming them:

> …they were so wonderful in giving us all the information they could, but not overwhelming us, which I appreciated 'cause I said, 'so, when am I gonna have to worry – when do I do that?', and she said, 'Not today. You know, today go home, right, just go home; we'll worry about that later' (Participant 108, female).

Feeling supported by the assessment team was operationally defined as perceived emotional and practical support, empathy, collaboration, and respect from the assessment professionals. Most CIs in this category addressed the assessment team's awareness and appreciation for the caregivers' emotional reactions to the process and diagnosis. The participants reflected on the importance of feeling like the assessment team was "in it" or "part of the team" with the family and the value of the assessment team respecting the caregiver's autonomy. For example, one participant stated:

> Well because then it felt like it was our decision. It wasn't like we were pressured to do it; it was, um, you're – you're doing this because it's going to help your child. It's not like, 'You HAVE to do this because this is what we think.' It was 'This is your decision,

> and you need to be comfortable in answering the questions that we're asking' (Participant 106, female).

Affirmations and reassurance about parenting involved acknowledgement of caregivers' parenting skills and abilities, knowledge of child's needs, and expertise. This category included experiences of validation and affirmation from the professionals. The participants stated that they felt reassured of their skills and efforts to support their child with ASD, which, in turn, alleviated their feelings of being at fault for their child's difficulties. One participant shared the following:

> At least our experience was we just felt – we felt heard, we felt validated, we felt encouraged, we felt inspired, and we never once felt like we were never doing enough for our son. They never made us feel like, 'Oh, here's a bunch of tools that you haven't thought of yet', you know, or – or, like, 'Well, have you tried this?' or 'Have you tried that?', and feeling, like, talked down to, and you're like, 'Yes, I've tried it all', and, um, they were like, 'I'm sure you've tried all this, and I'm sure that you're probably feeling this way about it, so we're gonna offer some suggestions – maybe you've heard them; maybe you haven't.' You know, like, they kind of didn't make you feel like, oh, you've done nothing for your kiddo, and we're gonna now come in and rescue you, and make you feel like we know everything.' They said, 'You know your son best; you have done incredible. If we can come along and support that process in ways that maybe you haven't thought of yet, we're gonna do that' (Participant 102, female).

Accurate representation and feedback about child's abilities was defined as the use of meaningful and accurate examples of child's behaviours, weaknesses, strengths, and abilities to clearly explain child's current level of function. The participants reported feeling more informed and knowledgeable about what was happening for their child when the professionals used specific and accurate examples from their child's behaviour. This feedback was offered both during the assessment process, through the use of informal debrief opportunities and during the diagnostic debrief session, through the use of specific examples to explain scores on the assessment measures. As one participant described:

> ...the psychologist… g[a]ve me a little bit of feedback on his ability. Not – like, she didn't – I was still – like, didn't know whether it would be autism or not, but it was obvious that there is a large scale of ability, so she was telling me a little bit about his learning style, and what that meant, regardless of diagnosis, you know, so, uh, that helped a little bit, on the day (Participant 101, female).

Ease of communication with assessment team involved the professionals' willingness, ability, and openness to ongoing communication with the caregivers. These participants reflected on the importance of having the diagnosing professional as a resource for follow-up questions and supports. For example:

> The doctor that we had was really – was really nice, and she – she did, of course, mention, like, if we needed to go back, … we could call her and try and get another appointment if we have any other concerns in the meantime, so it was kind of nice knowing that that's an option (Participant 110, female).

Positive and supportive treatment of child included the patient, gentle, and compassionate treatment of the child to increase the child's comfort and decrease child's anxiety during the assessment process. The CIs in this category included seemingly minor acts of compassion toward the child that had significant impact on the child's comfort in the assessment process.

This in turn strengthened the family resilience by easing the caregivers' feelings of concern and worry for their child. One participant described the following:

> when he had to go down to a room that he wasn't familiar with, one of his teachers would go with him, to begin with, to help to kind of make things a little more comfortable for him, but they were really good about, um – like, they went into the classroom to do their one observation, which was before he was taken out of the room with them, so that was nice because at least he was familiar with their faces (Participant 106, female).

Information about what to expect during the assessment process was defined as detailed descriptions, outlines, and expectations for the caregivers regarding the specific assessment process. These participants described the importance of feeling prepared and knowing what to expect so they could adequately prepare themselves and their child prior to the assessment. For example:

> I think, having my friend… in the experience, who was the occupational therapist, definitely, um, helped with it, and allowed me to anticipate a little bit of what to expect (Participant 101, female).

Multidisciplinary assessment team was defined as the collaboration of multiple different professional perspectives in completing a thorough and comprehensive assessment and addressing the multiple layers of the child's functional needs. Helping CIs in this category drew attention to the value caregivers place on the inclusion of multiple areas of expertise in the diagnostic process. One participant described:

> What I was very impressed about with [assessment centre] was that they were very thorough...So, that was good because I don't want some pediatrician going, 'Okay, so you filled out these papers, and I've seen her, kind of, you know, for half an hour, and oh

> yeah, I totally think she has autism.' So, we're talking about a lifelong diagnosis here, so they were very thorough (Participant 115, female).

Hope for the future included messages of hope about the child's strengths, abilities, and potential for success in his/her future. The participants described the importance of realistic hope and finding a balance between being hopeful and being realistic when sharing information about the child and the future. For example:

> For me the experience was good - our doctor was very kind, told us the news about [our child's] diagnosis and some different ways to keep getting help. But he didn't set limitations on her future. That was so important. As a parent you start to do that enough on your own of course. We weren't told "[your child] will only ever do this or [your child] will never be able to... etc." (Participant 112, female).

Hindering CI Categories

Table 2

Part I: Categories of Critical Incidents that were Perceived to Hinder Family Resilience

Category	PA	IN	%
Difficulties with assessment team members	4	8	**33**
Navigating government programs	4	5	**33**
Limitations of being in or near a smaller city centre	3	8	**25**
Lack of clarity of information	3	6	**25**
Format and delivery of assessment results	3	3	**25**
Accessing services	3	3	**25**
Misinformation/inaccurate information	2	3	17

Note. Participation rate > 25% are in boldface. PA = # of participants (N=12); IN = # of incidents (N=274); % = participation rate percentage.

Difficulties with assessment team members was the most frequently cited hindering category. This category was defined as interpersonal conflicts regarding both personal and professional behaviour of assessment team members. More specifically, participants described perceived lack of empathy, judgement, and disregard for caregivers' opinions, questions, and concerns. As well as, professionals being difficult to reach and not returning phone calls/emails when requested. One participant described the following:

> So, that was hard not having the best connection with her because she would have probably been the one to have the best supports and the best comfort, but it was very cold, very – it's like she may have told too many families, so she lost that empathy and sympathy (Participant 109, female).

Navigating government programs involved difficulties associated with awareness of and applying for government funding. These CIs included the emotional frustration participants felt in applying for funding, in navigating the necessary steps without support from professionals, and in being denied funding without adequate explanation. Additionally, the high case worker turnover and inconsistency in getting answers was highlighted as adding to participants' frustration. One participant described her frustration in initially being denied funding for her son:

> It is a fight to get those services; it is a fight to get the funding to get these kids what they need; it's a fight to get them into a school that's gonna actually listen to the therapist and keep those things in place. And you look at the amount of times – well, like [government program] denied him for specialized services, which is insane to me, and was insane to every other person (Participant 108, female).

Limitations of being in a or near a smaller city centre included difficulty with accessing quality services, supports, and resources in smaller or rural communities. Eight of the 12 participants were from communities outside of the major city centres and although only three participants identified this as being a hindering CI, all 8 mentioned the limitations when describing their journey through the assessment process. They discussed the difficulty of finding community-specific resources on their own because the assessment team was uninformed about the services offered in their home communities. For example, one participant stated:

> He – he knew of things in Calgary that he told me about, but it wasn't super helpful (laughs), um, yeah, so more just to continue doing what we were doing, parenting wise, but as far as supports and stuff, he – he and the nurse that was helping us, they didn't really – they didn't really know, yeah (Participant 113, female).

Lack of clarity of information involved professionals' use of technical and clinical terminology that left caregivers feeling confused and uncertain about the meaning of assessment outcomes. Specifically, participants highlighted the technical language used in the final assessment report and debrief, as well as feeling dissatisfied with the lack of clarity with which caregiver questions were addressed. One participant described the following:

> she just – she didn't – I don't – I'm just gonna use the term 'dumbed down' – but she didn't use terms that we could understand. She kept using big terms, and we only had such a limited amount of time, so I kept wanting to ask, like, 'Well, what does that actually mean to your everyday people? Like, I don't understand what that means' (Participant 109, female).

Format and delivery of assessment results was defined as the unexpected delivery of suggestions or assessment results that left caregivers feeling surprised and unsettled. The participants used terms like "blindsided" and "unprepared" when describing their reactions to unexpected information about their child. For example:

> then I really didn't like getting that letter in the mail … you get it in the mail, and it's, like, you know, got all the clinical this and that, and yeah, all these – all this stuff on it, right, and it's – so, I found that really hard. You know, so it mentions the summary, but it's, like, 'consideration of a global developmental delay may be warranted.' You're like, what's that?... I don't think it's right that they just – if you – they didn't even tell you that a letter's coming (Participant 112, female).

Accessing services was defined as limitations and barriers to accessing necessary supportive services before, during, and after the diagnosis. The participants highlighted difficulties associated with needing an official diagnosis to access services and therefore having limited or no access to services while on the waitlist. One participant also reported difficulties accessing services due to needing a physician on the assessment team:

> That's a part of why I feel like it was hard being diagnosed by the school team because there was no pediatrician/doctors name behind it 'cause everything we filled out – Active Start forms, his PARDS form had a whole sheet for the doctor (Participant 109, female).

Wish List Items

Table 3

Part I: Categories of Factors that were Believed to have Facilitated Family Resilience

Category	PA	IN	%
Complete orientation to assessment process	8	12	**67**
Clearly outlined information for accessing services	6	22	**50**
Awareness of and information about family's emotional needs	4	8	**33**
Access to funding and services	4	8	**33**
Available family mentorship	4	4	**33**
Modifying report, debrief, and feedback to parents' needs	3	7	**25**
Information about sharing the diagnosis with others	2	4	17
Waitlist supports	1	2	8

Note. Participation rate > 25% are in boldface. PA = # of participants (N=12); IN = # of incidents (N=274); % = participation rate percentage.

Complete orientation to assessment process was the WL category with the highest participation rate. It was defined as a clearly outlined and described orientation to the assessment process for both the child and the caregivers attending the appointments. The participants described a desire for more information about what the assessment will be like for the child, how involved the caregiver is allowed to be, how the time will be spent, the layout of the assessment location, the types of questions the caregivers may be asked, and what the possible outcomes of the assessment may be. Additionally, a need for a clear, step-by-step process for accessing diagnostic services within smaller communities was identified by this participant:

> But okay, okay, so what would have been helpful is to say, ‘Okay, so you’re on the autism spectrum disorder track. These are the things that you need to get assessed; these are the things that you need to have in place, um, in order for you to, um, see your pediatrician or see your family doctor, and then get a formal one in Calgary’, so that would have been really helpful (Participant 115, female).

Clearly outlined information for accessing services was defined as clear and specific information about supports offered by the assessment team, by community services, and by private organizations, as well as credible information sources. The participants described a need for better support in finding and accessing useful and relevant supports for their child’s specific needs. For example:

> Like, you just need – it’s up to us to find them. I think it needs to be more – you know, it just has to be more streamlined. Like, there’s too much for parents to have to deal with, day-to-day. To have to do all that is – is just – it’s just a lot… to have that kind of liaison, I guess, in between, would have been nice (Participant 110, female).

Awareness of and information about family’s emotional needs involved the assessment team’s accommodation for the participants’ emotional needs during the ASD diagnostic process. The participants identified things like receiving more reassurance, gentleness, emotional support from the professionals, the availability of social workers or counsellors at the debrief appointment, and more information regarding the benefits of counselling for caregivers with children with ASD. One participant also recommended the following:

> because you don’t want to feel like you can stay there for ever or, you know, or also even is there – I don’t know how long we could have waited in that room for, or if someone else needs the room, so yeah, I don’t know if you‘re allowed a certain amount of time, or

> if there's another, sort of, room, like, 'We have a few quiet rooms available for you to process this before you need to go in your car and drive home' (laughs), you know?...'Cause it really is, like – it really is a grief process for, I assume, a lot of people, yeah (Participant 112, female).

Access to funding and services involved the availability of holistic, family-oriented, recreational, in-home, and respite services in both large and small city centres. The WL items in this category described the participants' desire for more comprehensive services available through one or a few organizations to remove the burden from caregivers to navigate through finding and vetting the various resources available. One participant described the following:

> If we had, in the [our] region, something like Autism Calgary has that helps out these parents of newly diagnosed kids, that would be amazing...That would just be incredible. I wish there was more therapy options, rurally… (Participant 108, female)

Available family mentorship was defined as the organization of caregiver mentors who have gone through the assessment process to offer support, advice, and information to caregivers. The need for ongoing support from others who are aware of what the family is going through was emphasized by several participants. For example:

> So, having that person there to hold your hand a little bit, and like, help you through it is, yeah, I don't know if you can get like a buddy system going… (Participant 116, female).

Modifying report, debrief, and feedback to parents' needs was defined as the accommodation to caregivers' needs in providing assessment and diagnostic information. This WL category included the use of "parent-friendly" version of the diagnostic report, offering a follow-up debrief appointment for caregivers to ask questions about any information that they were still unclear on, and tailoring feedback to the personality and needs of each caregiver. Specifically, one participant stated:

> …it would be nice if they would maybe figure out, beforehand – like, the psychologist – what the best way would be to approach that family in telling them because you probably – I would hope you maybe could get a feel… (Participant 109, female).

Discussion

Specific and practical ways of endorsing family resilience have received relatively little examination within research literature, especially with respect to the ASD diagnostic assessment process and the role of professionals (Karst & Van Hecke, 2012). Research continues, however, to demonstrate the vital role family resilience plays in the optimal functioning of families (Harris & Glasberg, 2003). As Masten (2014) describes, family resilience is something that can be obtained and fostered by ordinary people through ordinary resources. Because family resilience is a dynamic process between risks and family strengths, those in contact with the family during times of risk are best situated to intervene in a positive way (Patterson, 2002). The participants within this study communicated a similar perspective as the aforementioned literature. They expressed the importance of family resilience for their family in managing the difficulties associated with having a child diagnosed with ASD. In addition, research indicates that professionals are often a key ingredient in promoting family resilience (Zand et al., 2013) and by focusing on family resilience, professionals are a first-line worker in the long-term success of these families. To date, virtually no research has examined the specific experiences of caregivers of children with ASD and the impact on their family resilience. The following discussion provides direct, practical, and necessary recommendations for professionals. Specifically, suggestions about what should be implemented and what should be avoided in all ASD diagnostic assessments process will be outlined.

Practical and Resource-Based Recommendations

Several of the helping and hindering CIs and the WLs were related to practical and resource-based experiences. These factors included informational support, family mentorship, assessment team style, and debriefing format. The recommendations outlined in this section can be implemented through practical planning, systemic changes, and professional networking.

Informational Support. Receiving valuable, practical, and specific information from professionals was one of the most important influences on participants' experiences of family resilience. This included a complete and thorough orientation to the assessment process so that families knew what to expect, advice about sharing the diagnosis with others, and clear and accurate representation of the child's abilities, strengths, and weaknesses. Additionally, some practical information was seen as going beyond the diagnostic information expected from the professional and included advice about accessing services both before (while on the waitlist) and after the diagnosis, recommendations for becoming involved in specific support communities, and an effort to answer the family's questions that had previous gone unanswered. Similarly, receiving inaccurate or misinformation from professionals was highlighted as significantly hindering family resilience. The value of practical advice or suggestions has been highlighted in resilience literature (Aymanns, Sigrun, & Klaur, 1995; Donnellan, Bennett, & Soulsby, 2015; Pinkerton & Dolan, 2007; Williams, Alexander, Bolsover, & Bakke, 2008) and suggests that the value of informational support is found both in emotional reassurance and in the specific steps that a caregiver can take. This information can be directly applied by services providers and is a practical and useful way to promote resilience in these families.

Family mentorship. Peer mentorship and support by others who understand and have been through similar difficult situations has also been established as a valuable resilience-building tool (Becvar, 2013; Jones, Killett, & Mioshi, 2018; McCrimmon & Montgomery, 2014). Although the participants identified online support groups as playing an important role in this support, they specifically identified the need for an organized caregiver support system established by the assessment team. The participants reported a need to be connected with someone who has been through the same process, with the same people, and who have experienced the same frustrations, disappointments, and grief they are currently navigating. By being put in communication with a mentor, the caregivers are saved the process of seeking out and finding the peer support that they desire and need. Assessment teams have a natural pool of peer mentors available to them. By asking each family's permission (i.e., would they be willing to be a mentor for another family in the future), the assessment team can create a system of family mentorship that promotes increased resilience in each family.

Assessment team style. Two factors that were directly related to the assessment team's make-up and style were the importance of having a multidisciplinary assessment team and having team members available for ongoing communication. Although the role multidisciplinary teams play in promoting resilience has not been found in the literature, it is clear that it is the recommended method an ASD assessment should be completed (Center for Disease Control and Prevention, 2001). The value of the multidisciplinary team was communicated through both helping and hindering CIs and participants corroborated the literature by reporting that the avenue by which multidisciplinary teams increased their resilience was through increasing their confidence in the professionals (MacVicar, Kirkpatrick, Humphrey, & Forbes-McKay, 2015) and acceptance of the diagnosis (Lietz, 2007). This recommendation implies that individual practitioners who are completing ASD diagnosis assessments should expand their network of professionals who can support the family, can assess other areas of functioning, and can contribute to a final diagnosis conclusion and service recommendations.

Several participants reported feeling that their resilience was hindered by the unavailability of the team after the final debrief appointment. By being unable to speak with the professional or having voicemails/emails go unanswered, the participants were left feeling unsupported and isolated. Conversely, those who found ease in their ongoing communication with the assessment team felt supported after the diagnosis was made. The value of communication in bolstering resilience is well-established (Lietz, 2007; Lin, Rong, & Lee, 2013; Stokar, Baum, Plishchke, & Ziv, 2014) and the value of having ease of communication with health care professionals has been identified as contributing to resilience (Hogden, Greenfield, Nugus, & Kiernan, 2012). By ensuring that at least one assessment team member is available for follow up questions, consultation, and support can significantly improve a family's resilience after a diagnosis has been made.

Debriefing format. The value of jargon-free communication between professionals and the general public is well-known and has been recommended for years by policy makers and service providers (Cicchetti & Toth, 1993; Huston, 1994; Knitzer, 1996; Luthar, 1999; Luthar & Cicchetti, 2000). Additionally, Brenner (2003) alluded to the connection between consumer-focused assessment reports and resilience by highlighting the value of maintaining a strength-based approach to human behaviour. The importance of presenting diagnostic information in a way that is understandable and compassionate is crucial to parental satisfaction during the debrief session (Cunningham, Morgan, & McGucken, 1984; Lingham & Newton, 1996). The participants in this study highlighted the frustration they felt at reports and debrief sessions filled with jargon and terminology that they did not understand. They identified the desire to have reports and debrief sessions that accommodate their needs as caregivers; including, jargon-free reports, child-specific examples, and clear recommendations and implications.

Additionally, timing was reported as being important for the participants' experiences of family resilience. Those participants who received their diagnosis quickly reported this as being a helping factor. This corroborates research findings that suggest that increased time in waiting for the final diagnosis amplified caregivers' feelings of dissatisfaction (Baird, McConachie, & Scrutton, 2000; Nursey, Rhode, & Farmer, 1991). By making an intentional effort to disclose the final diagnosis quickly after completing the assessment, professionals can help to enhance family resilience.

Emotional Support Recommendations

As is expected, the participants identified several emotional support-related helping and hindering CIs and WLs. The need to feel supported by the assessment team and the detrimental impact of uncompassionate, cold, or distant professional interactions on family resilience is of utmost importance. A supportive relationship requires the professional to demonstrate genuine concern, acceptance, empathy, warmth, and compassion (Ekas, Lickenbrock, & Whitman, 2010; Lin et al., 2013; Luthar & Cicchetti, 2000) throughout the assessment. The participants who reported helping CIs reported feeling like the professionals were on their team, were non-judgmental, and were not rushing through the participants' questions and concerns. Conversely, the participants who reported hindering CIs perceived the professionals as lacking in empathy, cold, dismissive, and rushed. Professionals have a very important diagnostic task that requires being objective, clinical, and scientific, but in order for families to make the most of the diagnosis, they need to be emotionally supported and prepared to do so. This requires professionals to be aware of caregivers' emotional needs (including allowing caregivers time to process information and their emotions), provide information on the possible need for external emotional support (i.e., counselling), and to prioritize supporting families' emotional needs during the diagnosis assessment process.

Another important emotional support professionals can offer is the affirmation of parenting skills (Kiplinger & Browne, 2014). Participants highlighted the value of feeling affirmed of their parenting decisions, abilities, and insights, and feeling reassured that they were not at fault in some way for their child's ASD diagnosis. Emotionally aware professionals can promote family resilience and confidence by integrating encouragement and affirmations into their discussions with the family, validating the caregiver's role as expert on their own child, and not making assumptions about what the caregivers have or have not already tried. Directly connected to affirmations of parenting skills is the need for messages of hope about the child's future (Faso, Neal-Beevers, & Carlson, 2012; Zand et al., 2013). The participants indicated that it was important to hear realistic hope. More specifically, receiving information about the child's future that was strengths focused increased participants' feelings of family resilience only when that information seemed realistic. Professionals can provide messages of hope by sharing specific examples of the child's areas of strength and stories of other children's progress and success while reminding the caregivers that the child's future may look different – not necessarily worse – but different than what they had originally expected or planned.

Finally, the way the child is treated during the assessment process can have a significant impact on family resilience. As caregivers observe the treatment of their child, they take notice of the support, care, patience, and kindness the professionals show (Bowers, 2015). When a caregiver feels the professional has taken time to truly get to know their child, enjoys being with their child, and wants to see their child be successful, they are more likely to feel confident and secure throughout the process. This security and confidence leads to a sense of family resilience and promotes a sense that they could trust the outcome of the diagnosis process.

Systemic Recommendations

The last group of categories identified from the participants' helping CIs, hindering CIs, and WLs are related to systemic challenges faced by caregivers during the ASD diagnosis process. These categories were all identified as either hindering their family resilience or were described as wish list items. These systemic recommendations are all related to barriers to services. When caregivers face barriers to accessing supports for their child, they experience decreases in resilience, hope, optimism, and increases in depressive symptoms (Taylor & Warren, 2012). More specifically, the participants identified navigating and accessing government programs and funding, accessing services without a formal diagnosis, and limited availability of services in rural or smaller city centres as having a negative impact on their family resilience. Although individual professionals may have little control over these factors, being aware of them and communicating their presence to individual families may help to protect families from their resilience-hindering impact.

Limitations and Future Research

Several limitations should be considered when understanding these research findings. First, because these caregivers chose to participate in a study looking at resilience, they were likely individuals who experienced a greater degree of resilience than many of their peers, which may have resulted in a sample of parents who had relatively positive experiences during the ASD diagnostic assessment. It is possible that with a larger and more randomized sample of caregivers, there may have been a more equal number of helping and hindering CIs identified, which may have provided a more balanced view of the ASD diagnostic assessment process.

Second, the participants' children were all given the diagnosis of ASD. Including participants who had gone through the diagnostic process and did not receive the diagnosis of ASD may have provide additional useful recommendations. Third, family resilience was evaluated only from the perspective of a primary caregiver. This limits the findings to what caregivers may find helpful and hindering and may then create a skewed perspective of family resilience in this context.

Finally, the participants were all female primary caregivers of the child recently diagnosed with ASD. This suggests that, although the findings reveal many categories of incidents that contribute to family resilience, they are all taken from the perspective of mothers. With further investigation into fathers' experiences, there may well be additional important factors that help and hinder family resilience that have yet to be uncovered.

This study confirms existing research and brought new insight into different professional experiences that have helped and hindered families' experiences of family resilience during the ASD diagnostic process. Nevertheless, future research should involve a more in-depth exploration of these factors and should aim to quantitatively measure the impact the ASD diagnostic assessment has on family resilience (i.e., pre- and post-assessment measurement of family resilience) in order to scientifically confirm the impact professionals have on the promotion of family resilience. The systematic application of therapeutic assessment strategies, as defined by Tharinger et al. (2009) should be further applied and evaluated with this population. Additionally, questions around whether similar helping and hindering factors are perceived to be important for families from other geographical regions and for families with older children being diagnosed with ASD have yet to be addressed and will help to establish the usefulness of this research for professionals in other areas. Finally, research involving the application of the aforementioned factors and the various suggestions for service delivery (i.e., randomized control trials, or longitudinal studies) can demonstrate the specific impact each factor and recommendation has and can help to inform professionals of their direct impact on family resilience, as well as help to develop an evidenced-base for how to promote family resilience during the ASD diagnostic assessment process.

References

Alvord, M. K., & Grados, J. J. (2005). Enhancing resilience in children: A proactive approach. *American Psychological Association, 10*, 735-828. doi: http://dx.doi.org/10.1037/0735-7028.36.3.238

Avramidis, E., Bayliss, P., & Burden, R. (2000). Student teachers' attitudes toward the inclusion of children with special educational needs in the ordinary school. *Teaching and Teacher Education, 16*, 277-293. doi: 10.1016/S0742-051X(99)00062-1

Aymanns, P., Sigrun, H., & Klaur, T. (1995). Family support and coping with cancer: Some determinants and adaptive correlates. *British Journal of Social Psychology, 34*, 107-124. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.2044-8309.1995.tb01051.x

Baird, G., McConachie, H., & Scrutton, D. (2000). Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood, 83*, 475-480. http://dx.doi.org/10.1136/adc.83.6.475

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*, 702-714. doi: 10.1111/j.1365-2788.2007.00960.x

Becvar, D. S. (Ed.). (2013). *Handbook of family resilience.* New York, NY: Springer.

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012). Resilience in family members of persons with autism spectrum disorder: A review of the literature. *Issues in Mental Health Nursing, 33*, 650-656. doi: 10.3109/01612840.2012.671441

Bowers, A. (2015). *The experience of mothers and clinicians in the assessment of autism spectrum disorder* (Master's Thesis). Retrieved from https://open.library.ubc.ca/cIRcle/collections/ubctheses/24/items/1.0166483#downloadfiles

Brenner, E. (2003). Consumer-focused psychological assessment. *Professional psychology, 34*, 240-247. doi: 10.1037/0735-7028.34.3.240

Butterfield, L.D., Borgen, W.A., Amundson, N.E., & Maglio, A.S.T. (2005). Fifty years of the critical incident technique: 1954-2004 and beyond. *Qualitative Research, 5*, 475-497.

Butterfield, L. D., Borgen, W. A., Maglio, A. T., & Amundson, N. E. (2009). Using the enhanced critical incident technique in counselling psychology research. *Canadian Journal of Counselling, 43*, 265-282.

Center for Disease Control and Prevention. (2001). Frequently asked questions about autism. Atlanta, GA: Center for Disease Control.

Cicchetti, D., & Toth, S. L. (Eds.). (1993). *Child abuse, child development, and social policy.* Norwood, NJ: Ablex.

Cunningham, C. C., Morgan, P., & McGucken, R. B. (1984). Down's syndrome: Is dissatisfaction with disclosure of diagnosis inevitable? *Developmental Medicine and Child Neurology, 26*, 33-39. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.1469-8749.1984.tb04403.x

Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & Mental Health, 19*, 932-939. doi: 10.1080/13607863.2014.977771

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 1274-1284. doi: 10.1007/s10803-010-0986.y

Evans, A. (2010). *Parents' responses to their child's diagnosis of autism spectrum disorder (ASD)* (Doctoral dissertation). Retrieved from http://eprints.soton.ac.uk/172757/1.hasCoversheetVersion/Thesis_-_Amber_Evans.pdf

Faso, D. J., Neal-Beevers, A. R., & Carlson, C. L. (2012). Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*, 288-297. http://dx.doi.org/10.1016/j.rasd.2012.08.014

Fiese, B. H. (2006). *Family routines and rituals.* New Haven, CT: Yale University Press.

Finn, S. E. & Tonsager, M. E. (1992). Therapeutic effects of providing MMPI-2 test feedback to college students awaiting therapy. *Psychological Assessment, 4*, 278-287.

Glass, P. W. (2001). *Autism and the family: A qualitative perspective* (Doctoral dissertation, Virginia Polytechnic Institute and State University). Retrieved from http://www.researchgate.net/profile/Marilyn_Lichtman/publication/253191008_AUTISM_AND_THE_FAMILY_A_QUALITATIVE_PERSPECTIVE/links/02e7e52a758983b89c000000.pdf

Harris, S., & Glasberg, B. (2003). *Siblings of children with autism: A guide for families.* Bethesa, MD: Woodpine Press.

Hogden, A., Greenfield, D., Nugus, P., & Kiernan, M. C. (2012). What influences patient decision-making in amyotrophic lateral sclerosis multidisciplinary care? A study of patient perspectives. *Patient Preference Adherence, 6*, 829-838. doi: 10.2147/PPA.S37851

Huston, A. C. (1994). Children in poverty: Designing research to affect policy. *Social Policy Report: Society for Research in Child Development, 8*(2), 1-12.

Jones, S. M., Killett, A., & Mioshi, E. (2018). What factors predict family caregivers' attendance at Dementia Cafés. *Journal of Alzheimer's Disease, 64*, 1337-1345. doi: 10.3233/JAD-180377

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of Autism Spectrum Disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychological Review, 15*, 247-277. doi: 10.1007/s10567-012-0119-6

Kiplinger, V. L., & Browne, C. H. (2014). *Parents' assessment of protective factors: User's guide and technical report*. New York, NY: Center for the Study of Social Policy.

Knitzer, J. (1996). Children's mental health: Changing programs and policies. In E. F. Zigler, S. L. Kagan, & N. W., Hall (Eds.), *Children, families, and government: Preparing for the 21st century* (pp. 207-232). New York, NY: Cambridge University Press.

Li, F., Godinet, M. T., & Arnsberger, P. (2011). Protective factors among families with children at risk of maltreatment: Follow up to early school years. *Children and Youth Services Review, 33*, 139-148. doi: 10.1016/j.childyouth.2010.08.026

Lietz, C. A. (2007). Uncovering stories of family resilience: A mixed methods study of resilient families, part 2. *Families in Society: The Journal of Contemporary Social Services, 88*, 147-155. doi: 10.1606 / 1044-3894.3602

Lin, F., Rong, J., & Lee, T. (2013). Resilience among caregivers of children with chronic conditions: A concept analysis. *Journal of Multidisciplinary Healthcare, 6*, 323-333. http://dx.doi.org/10.2147/JMDH.S46830

Lingham, S., & Newton, R. (1996). *Right from the start: The way parents are told that their child has a disability.* London, UK: British Pediatric Association.

Luthar S. S. (1999). *Poverty and Children's adjustment.* Thousand Oaks, CA: Sage.

Luthar, S. S., & Cicchetti, D. (2000). The construct of resilience: Implications for interventions and social policies. *Development and Psychopathology, 12*(4), 857-885.

MacVicar, S., Kirkpatrick, P., Humphrey, T., & Forbes-McKay, K. E. (2015). Supporting breastfeeding establishment among socially disadvantaged women: A meta-synthesis. *Birth: Issues in Perinatal Care, 42*, 290-298. https://doi.org/10.1111/birt.12180

Masten, A. S. (2007). Resilience in developing systems: Progress and promise as the fourth wave rises. *Development and Psychopathology, 19*, 921-930. doi: 10.1017/S0954579407000442

Masten, A. S. (2001). *Ordinary magic: Resilience processes in development.* Minneapolis, MN: University of Minnesota, Twin Cities Campus.

Masten, A. S. (2014). *Ordinary magic: Resilience in development.* New York, NY: The Guilford Press.

Masten, A. S., & Garmezy, N. (1985). Risk, vulnerability, and protective factors in developmental psychopathology. *Advances in Clinical Psychology, 8*, 1-52. doi: 10.1007/978-1-4613-9820-2_1

Masten, A. S., & Obradović, J. (2006). Competence and resilience in development. *Annals of the New York Academy of Sciences, 1094*, 13-27. doi: 10.1196/annals.1376.003

Masten, A. S., Garmezy, N., Tellegen, A., Pellegrini, D. S., Larkin, K., & Larsen, A. (1988). Competence and stress in school children: The moderating effects of individual and family qualities. *Journal of Child Psychology and Psychiatry, 29*, 745-764. doi: 10.1111/j.1469-7610.1988.tb00751.x

Mazzucchelli, T., & Sanders, M (2012). *Stepping stones triple P: A population approach to the promotion of competent parenting of children with disability*. Queensland, Australia: University of Queensland.

McCrimmon, A. W., & Montgomery, J. M. (2014). Resilience-based perspectives for Autism Spectrum Disorder. In S. Prince-Embury, & D. H. Saklofske (Eds.), *Resilience Interventions for Youth in Diverse Populations* (pp. 375-396). New York, NY: Springer Science+Business Media.

Nursey, A. D., Rhode, J. R., & Farmer, R. D. T. (1991). Ways of telling new parents about their child and his or her mental handicap: A comparison of doctor's and parents' views. *Journal of Mental Deficiency Research, 35*, 48-57. https://doi.org/10.1111/j.1365-2788.1991.tb01030.x

Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family, 64*, 349-360. doi: 10.1111/j.1741-3737.2002.00349.x

Pinkerton, J., & Dolan, P. (2007). Family support, social capital, resilience and adolescent coping. *Child and Family Social Work, 12*, 219-228. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.1365-2206.2007.00497.x

Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry, 57*, 316-331. doi: 10.111/j.1939-0025.1987.tb03541.x

Stokar, Y. N., Baum, N. L., Plischke, A., & Ziv, Y. (2014). The key to resilience: A peer based youth leader training and support program. *Journal of Child and Adolescent Trauma, 7*, 111-120. doi: 10.1007/s40653-014-0016-x

Taylor, J. L., & Warren, Z. E. (2012). Maternal depressive symptoms following autism spectrum diagnosis. *Journal of Autism and Developmental Disorders, 42,* 1411-1418. doi: 10.1007/s10803-011-1375-x

Tharinger, D. J., Finn, S. E., Gentry, L., Hamilton, A., Fowler, J., Matson, M., … Walkowiak, J. (2009). Therapeutic assessment with children: A pilot study of treatment acceptability and outcome. *Journal of Personality Assessment, 91*, 238-244. doi: 10.1080/00223890902794275

Truitt, M., Biesecker, B., Capone, G., Bailey, T., & Erby, L. (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling, 87*, 233-238. doi: 10.1016/j.pec.2011.08.015

Walsh, F. (2010). A family resilience framework for clinical practice: Integrating developmental theory and systemic perspectives. In W. Borden (Ed.), *Reshaping theory in contemporary social work: Toward a critical pluralism in clinical practice* (pp. 146-176). New York, NY: Columbia University Press.

Williams, R., Alexander, D. A., Bolsover, D., & Bakke, F. K. (2008). Children, resilience and disasters: Recent evidence that should influence a model of psychosocial care. *Current Opinion in Psychiatry, 21*, 338-344. doi: 10.1097/YCO.0b013e328305b6e4

Zand, D. H., Braddock, B., Baig, W., Deasy, J., & Maxim, R. (2013). Role of pediatricians in fostering resilience in parents of children with autism spectrum disorder. *The Journal of Pediatrics, 163,* 1769-1771. doi: doi:10.1016/j.jpeds.2013.06.074

CHAPTER FOUR: Promoting Family Resilience through the ASD Diagnostic Assessment:

Part II: Helping and Hindering Factors for Families

Caregivers' of newly diagnosed children with Autism Spectrum Disorder (ASD) are often left in distress, doubt, and indecision (Evans, 2010). They are left wondering and worrying about how they are going to help their family cope with the long term, difficult, and stressful consequences of ASD (Glass, 2001). Caregivers who are adequately prepared are in the best position to maintain and facilitate family resilience during difficult and stressful experiences; namely, the ASD diagnosis process. By hearing from caregivers who have recently navigated the ASD diagnosis process and identified the incidents and factors that were relevant to their family resilience, it is possible to assist new caregivers in the promotion of their family resilience. This article, the second in a two-part series, specifically addressed the implications of this research for families navigating the ASD diagnosis process.

In Part I of this study, the literature related to professional promotion of resilience in families was considered, a description of the research design was discussed, and the research findings relative to the professional factors that help and hinder family resilience, as well as the items that participants wished professionals would provide or consider while working in the ASD field was provided. This paper, Part II, addresses the resiliency helping and hindering incidents, as well as the wish list items, that are relevant to the parents, caregivers, and families of children going through the ASD diagnosis process. To begin, a literature review examines the role of caregivers in facilitating family resilience in the presence of ASD. This will be followed by a brief description of the research design and methodology. Finally, the research findings highlighting the helping incidents, hindering incidents, and wish list items, as well as a discussion of the application of these findings to caregivers and professionals will be discussed.

Literature Review

The previous resilience research can be applied to most, if not all, families, but families with developmental disabilities face a unique set of challenges and demands, and, therefore, require special considerations. Despite the extraordinary demands placed on families of children with ASD, many of these families demonstrate resilience (Bayat, 2007). Naturally, it can be assumed that there are positive aspects of raising a child with ASD. By reminding families of these positive aspects or encouraging them to place emphasis on the positive, families are better equipped to remain resilient even during the most trying times.

Resilience is the ability to balance between risk and protective abilities (Patterson, 2002). Families with a child with ASD face a unique set of risk factors that require a unique set of protective factors (Bekhet, Johnson, & Zauszniewski, 2012b). Factors such as symptom severity (i.e., the higher the severity rating the greater the risk factor) can place extra demands on the family supporting the individual with ASD (Benson & Karlof, 2009; Hartley, Barker, Seltzer, Greenberg, & Floyd, 2011). Research has demonstrated that higher rates of ASD symptomatology leads to negative outcomes in caregiver's mental health, life satisfaction, and emotional closeness. Marital quality also affects a family's resilience in the face of ASD (Hartley et al., 2011). Caregivers of children with ASD tend to have lower relationship satisfaction. Additionally, lower relationship satisfaction is related to higher levels of stress, more burdens, and less adaptability and cohesion with the marital relationship (Brobst, Clopton, & Hedrick 2009; Hartley et al., 2011; Higgins, Bailey, & Pearce, 2005). Ultimately, the potential negative influence of ASD on a caregiver is pervasive and significant. In cases where two caregivers live in the same home, each parent's individual ability to cope with emotional reactions can affect the family's resilience. Anger is a common reaction for caregivers of children with ASD, but it can have negative influences on the family as a whole. For example, higher levels of parental anger are related to stress, depression, lower marital quality, and lower overall emotional well-being (Benson & Karlof, 2009; Siman-Tov & Kaniel, 2011). Finally, having more than one child with ASD is a risk factor to a family's well-being and can threaten resilience. Families with more than one child with ASD are at greater risk for lower life satisfaction, lower well-being, greater negative affect, and higher incidents of depression (Ekas & Whitman, 2010). Given the increased chance of these risk factors, how do families with ASD demonstrate resilience?

Just as there are unique risk factors associated with families in the presence of ASD, there are also unique protective factors that can promote resilience (Bekhet et al., 2012b). Social support has been identified numerous times in the literature as an important protective factor for families with a child with ASD (Brobst et al., 2009; Carter, Martinez-Pedraza, & Gray, 2009; Ekas, Lickenbrock, & Whitman, 2010; Hall & Graff, 2011; Tobing & Glenwick, 2007). Quality social support is related to lower maternal distress, stress, depression, and negative affect, as well as a greater ability to cope with the children and higher relationship satisfaction. In addition, family members' sense of control over their lives and events is a significant protective factor for families with a child with ASD. More specifically, an internal locus of control allows families members to better manage the stress associated with living with ASD (Siman-Tov & Kaniel, 2011). One's ability to modify the way one thinks about a stressful situation is a key element of coping. Positive reinterpretation, meaning making, and humour can assist people in their attempt to thrive during devastating life events (Bayat, 2007; Terry & Hynes, 1998). Finally, Ekas, Whitman, & Shivers (2009) identified the key role that religiosity and/or spirituality can play in facilitating resilience during difficult times. Religious beliefs and activities protect families of children with ASD against hopelessness and depression (Luong, Yoder, & Canham, 2009).

As is evidenced above, families with children with ASD have a large number of demands and risk factors, but they also possess important protective factors that allow them to be resilient in times of difficulty. By utilizing these protective factors, families are given the opportunity to experience self-efficacy, acceptance, coherence, optimism, positive family functioning, and enrichment (Bekhet et al., 2012b). These experiences are key indicators of resilience for families with a child with ASD and can result in many positive outcomes (i.e., parental mental health, better marital quality, better psychological well-being, and higher life satisfaction; Carter et al., 2009; Ekas et al., 2010; Kuhn & Carter, 2006; Siman-Tov & Kaniel, 2011; Tobing & Glenwick, 2007) for the whole family (Van Breda, 2001). Additionally, family connectedness, affirmation of individual family members' strengths, and demonstrating increased compassion for others are considered evidence of family resilience (Bayat, 2007). When families can pull together resources and remain connected to one another, they are better equipped to problem-solve and work together. In order to work together successfully, resilient families remain open to learning lessons of patience and compassion and value each member for their differences and strengths.

Families with children with ASD cannot necessarily control the risk factors they face, but they can strengthen (either on their own or with professional help) their protective factors, which will result in greater overall family resilience (Bekhet et al., 2012b). The assumption that families faced with raising a child with ASD function at a less than optimal level has largely been refuted. Some families – families demonstrating resilience – actually grow, improve, and become strengthened as a result of the adversity they have faced (Bayat, 2007). Caregivers play an exceedingly important role in the resilience of their family. They are given a unique opportunity to demonstrate the kinds of characteristics, adaptability, and growth that are necessary for remaining resilient, which can promote resilience in the rest of the family.

Caregiver Resilience in the Presence of ASD

Caring for a child with ASD creates a unique set of challenges. While a child typically becomes autonomous, managing their own decisions, consequences, and reactions, children with ASD remain dependent on their caregivers (Bekhet et al., 2012b). As a result, caring for a child with ASD can be very costly to caregivers' physical, financial, and mental health (Gray, 2006). Caregivers of children with ASD deal with higher degrees of stress, anxiety, and depression than the normative population. This is often a result of not feeling equipped to manage the increased demands associated with their child's needs. Yet, some caregivers of children with ASD seem to thrive, resulting in positive outcomes (i.e., meaning making, empowerment, and optimism; Bayat, 2007). The important role caregivers' play in the lives of their children has been established; therefore, the important function of caregiver resilience is implied. How then do caregivers demonstrate resilience in the face of adversity?

Caregiver protective factors are a useful tool in understanding how caregivers become resilient. Bekhet, Johnson, and Zauszniewski (2012a) evaluated how the protective factor of positive cognitions promoted the resilience indicator of resourcefulness for caregivers of children with ASD. Their study demonstrated that positive cognitions mediated the relationship between caregiver burden and resourcefulness. In other words, caregiver burden influences caregiver resourcefulness, but a caregiver's positive cognitions strengthens that relationship. Enhancing positive social support is another key factor to promoting resilience in caregivers (Boyd, 2002). Both formal and informal social supports are predictive of positive outcomes (optimism, positive affect and life satisfaction; Ekas et al., 2010).

Using protective factors to promote caregiver resilience can have significant positive influence on the family. Low levels of resilience can effectively buffer the negative outcomes of anxiety and depression in caregivers of children with ASD (Bitsika, Sharpley, & Bell, 2013). With appropriate intervention chronic stress, anxiety and depression can be faced with resilience (Barker, Mailick, & Smith, 2014). El-Ghoroury (2012) conducted a qualitative evaluation of caregivers of children with ASD to identify key characteristics of caregiver resilience in the presence of ASD. He highlighted the importance of understanding one's child with ASD beyond the ASD symptoms. These children have personalities that can be nurtured and honoured. Resilient caregivers have an ability to see the unique characteristics of their children beyond the ASD. Additionally, he also identified the need for caregiver and child autonomy. Caregivers who are able to balance their child's independence, appropriate support for their child, and their own need for autonomy demonstrate more resilience than those who cannot find a healthy balance. Finally, El-Ghoroury highlighted the important caregiver task of accessing necessary resources for their child with ASD. This task can be overwhelming and daunting, and yet, resilient caregivers are equipped to advocate for their child, ask for help when needed, and successfully navigate the social services system.

In summary, evidence shows that by fostering protective factors (i.e., positive cognitions, positive social support, and internal locus of control) caregivers demonstrate indicators of resilience (such as, resourcefulness, optimism, and self-efficacy) and are more equipped to face the challenges of raising a child with ASD (Bekhet, et al., 2012a; Ekas et al., 2010; Siman-Tov & Kaniel, 2011). Resilient caregivers have the ability to manage increased levels of stress, anxiety, and depression, as well as the ability to see beyond the diagnosis and the disorder, to allow their children and themselves to have appropriate levels of autonomy, and to manage the difficult task of finding resources for their child (El-Ghoroury, 2012).

The Present Study

An examination of the literature reveals that very little is known about the specific parental experiences that help and/or hinder family resilience during the ASD diagnostic process. As one step in addressing this gap in the literature, the researchers sought to answer the over-arching question: What experiences help and hinder a caregiver's or caregivers' perceptions of family resilience during the ASD diagnostic assessment process? This study – Part II of the larger study – uses different data from our sample of participants to address the unique personal and familial experiences of caregivers as they navigate the ASD diagnosis process and consider the impact on family resilience.

In order to guide the interview process, three specific qualitative research questions were developed. They are:

1. What incidences help caregivers' experiences of family resilience during the ASD diagnostic assessment process?
2. What incidences hinder caregivers' experiences of family resilience during the ASD diagnostic assessment process?
3. What do caregivers believe could have helped their experiences of family resilience during the ASD diagnostic assessment process?

Methodology

The Enhanced Critical Incident Technique (ECIT) was used to understand the participants' answers to these questions. ECIT was the appropriate choice for this study because it allowed the researcher to build rapport with the participants, it accounted for the participants' perspectives and contexts, and it allowed for probing and follow-up questions to promote deeper and more meaningful understanding of the participants' experiences. ECIT is a helpful method for under-researched areas because of the structured investigation of the specific incidents that helped and hindered the experience of a particular phenomenon, as well as the participants' thoughts about what may have been helpful (wish list items), allowing for the practical application of the findings.

Recruitment

Inclusion and exclusion criteria were defined because of the structured nature of the desired sample. Caregivers' perception of the ASD diagnosis process and its influence on family resilience was a primary criterion for this study, therefore the following inclusion criteria was established: the participants are all caregivers in a family with at least one child; the families included at least one child recently (within the year prior to the interview) diagnosed with Autism Spectrum Disorder; and, the diagnosis needed to have been completed in Alberta, Canada. Posters with the above criteria were distributed through social media, doctors' offices, private practices, and public notice boards. A $20 gift card was offered to all participants.

Participants

The sample consisted of 12 female caregivers; 11 Caucasian, and one Haitian-Canadian. All the participants were between the ages of 27 and 41 and 10 were born in Canada, while 2 participants were born in England. The children recently diagnosed with ASD were between three and nine years old and were 83% male and 17% female. At the time of the interviews, 58% of participants had completed some college education, 33% had university degrees, and 8% had completed high school as their highest level of education. The participants reported their yearly total household income as follows: 33% within the $51, 000 to $70, 000 range; 33%

within the $91, 000 to $110, 000 range; 8% within the $71, 000 to $90, 000 range; 8% within the $111, 000 to $130, 000 range; 8% in the $171, 000+ range; and, 8% chose not to disclose income information. In terms of religious or cultural affiliations, 42% indicated they had no religious or cultural affiliation, 33% identified as Christian, 8% identified as agnostic, 8% as Catholic, and 8% as Latter-Day Saints.

Data Collection

After completing an informed consent (Appendix A), individual semi-structured interviews (Appendix B) were conducted with each participant. The interviews were audio-recorded, with the participants permission, to increase the studies validity. The interviews lasted between 45 minutes to one hour and 45 minutes each. Each interview began with the participants describing their family's diagnosis process, their understanding of family resilience, and the impact they perceived the diagnosis process had on their family resilience. The interview then concluded with questions regarding the participants' expectations of the diagnosis and their responses to receiving a diagnosis of ASD.

During the structured portion of the interview, participants were asked to reflect on their recent ASD diagnosis appointment and identify what specifically in that appointment helped them to feel more resilient and what incidences in their diagnosis appointment made it more difficult to feel resilient. Finally, participants were asked to identify items and factors that they believe would have helped them experience more family resilience.

Credibility checks are used to confirm the importance of the identified incidents, the accuracy of the interpreted data, and the participants' agreement with the organized incidents, factors, and categories. These credibility checks were completed by sending electronic summaries of the data to all 12 participants.

Data Analysis

Data analysis began by extracting the critical incidents (CI) and the wish list items (WL) from each interview. These CIs and WLs were identified by the participants' specifically stating and describing the incidents' impact on their family resilience. Categories were then created to group the extracted CIs and WLs. As recommended by Butterfield et al.'s (2005; 2009), eight credibility checks were conducted to improve the quality of the findings: (a) audiotaping the interviews; (b) interviewer fidelity; (c) exhaustiveness (ensuring that no new categories are possible after the final interview has been coded); (d) participation rates (categories were considered to be valid if they were identified by at least 25% of the participants); (e) placing incidents into categories by an independent judge; (f) cross-checking by participants; (g) expert opinions; and, (h) theoretical agreement (identifying overlap with existing literature and the possibility of novel information). Finally, category titles and operational definitions were written for each group of identified incidents and items.

Researcher-As-Instrument

Despite the structured nature of ECIT, it is not free from researcher subjectivity and bias. Researcher's assumptions, biases, and expectations are present in all qualitative research and thus the interviews are conducted, understood, and analyzed in light of the researcher's beliefs.

The author acknowledges an assumption that raising a child with ASD can be a rewarding and enjoyable experience when provided with the necessary tools and resources to do so and a bias that the diagnostic process is often less supportive and validating than caregiver's need to feel resilient. The author maintains the assumption that all people are capable of facing challenging situations successfully and that promoting resilience is an effective way to hep caregivers feel prepared to do so. These beliefs and perspectives created a lens through which the interviews, data analysis and findings were conducted and understood.

Findings

Various expectations and reactions were identified by the 12 participants. Thirty-three percent of participants reported that they expected the diagnosis, 25% expected a diagnosis but not necessarily ASD, 25% expected the diagnosis but their husband did not and, 17% did not expect the ASD diagnosis at all. One-third of the participants experienced relief at receiving the diagnosis of ASD and stated that it helped them feel affirmed in the decision-making regarding their child. The remaining two-thirds experienced feelings of shock, surprise, grief, guilt, denial, and self-blame after receiving confirmation of the official ASD diagnosis.

As described in Part I, the participants were asked to provide their own personal definition of family resilience. The following definition was compiled from their responses: family resilience is the whole family's acceptance of the difficult situation and moving forward with a healthy emotional, mental, and spiritual life together; the ability to "bounce back" after receiving the diagnosis of ASD and to grow and adapt in a positive way. Family resilience is the ability to fight and advocate for the family by identifying supports that will help the family to function and thrive during the difficult experience.

The 12 participants described a total of 274 helping and hindering critical incidents and wish list items divided into a total of 18 helping categories, 13 hindering categories, and 10 wish list categories. Further, the categories were divided into two groups; factors that are relevant to professionals in the ASD diagnosis field (Part I) and factors that are relevant for family decision making and navigation of the ASD diagnosis process. Only the factors with direct implications to caregivers and families will be described in this paper. For information regarding the role professionals play in fostering family resilience, refer to Part I of this study. For Part II, there were 54 helping CIs organized into 6 categories (Table 4), 49 hindering CIs organized into 6 categories (Table 5), and 4 WLs organized into 2 categories (Table 6). Only CIs with participant rates of at least 25% will be further discussed and both WLs will be discussed given the small number of categories identified.

Helping CI Categories

Table 4

Part II: Categories of Critical Incidents that were Perceived to Help Family Resilience

Category	PA	IN	%
Emotional support from friends and family	10	16	**83**
Access to community supports	8	14	**67**
Parents' attitude and outlook	6	13	**50**
Counselling/professional emotional support	5	6	**42**
Child's characteristics and qualities	3	3	**25**
Previous experiences of resilience	2	2	16

Note. Participation rate > 25% are in boldface. PA = # of participants (N=12); IN = # of incidents (N=274); % = participation rate percentage.

Emotional support from friends and family was endorsed by the largest number of participants. It was defined as the perceived emotional and practical support, empathy, advice, and respect from friends and family in the participants' community. The participants reported the importance of having other parents to connect with and to gain emotional support from. They also highlighted the value of having a spouse that was fully engaged in the process and who was emotionally supportive even if they could not be physically available for appointments.

Additionally, the value of establishing friendships with other caregivers of children with ASD was described as contributing to family resilience. For example:

> having, like, met a few parents with autistic kids, you're like, 'wow, like, I get you' (Participant 115, female).

Access to community supports was operationally defined as the participants becoming involved in community-based supports (online support groups, community run organizations, and child-based intervention services) prior to the official diagnosis. The participants report the openness of most support groups in accepting caregivers without the official diagnosis. They stated that they not only gained emotional support from other caregivers going through the waiting process, but also that they were able to gather more information more quickly than if they were waiting for professional support. For example, one participant stated:

> With autism, but also, I dunno, like, special needs in general. Like, yeah, you never know who is dealing with what, and yeah, so that's – for me that's been a help to ask questions (online) and get quick answers 'cause if it's via professionals, it takes such a long time, so yeah (Participant 110, female).

Parents' attitude and outlook involved the attitude and demeanour that the participants possessed prior to engaging in the diagnostic process and with which they actively chose to employ during the diagnostic process. This category included experiences of maintaining a positive family attitude, prioritizing advocacy for the child, and religious and spiritual beliefs that there was a plan for the family. The participants spoke about the importance remaining persistent and confident in their skills and abilities, as well as in breaking problems down into smaller manageable pieces. One participant described how she was able to maintain her tough advocacy for her child:

> You go through this huge journey with all of this, and not just your kid. Like, I feel like my world's been turned upside down, and some of it's not for the worse, and so some of it I feel I've become, you know, more open to other people and probably more in the moment, and all of those kinds of things, which aren't bad things (laughs), you know... You know, even probably more compassionate and more understanding… now I get it 'cause, like, that wouldn't have affected me that way, but okay, now I understand that, you know... So, it's been quite life changing, I think, in a lot of ways (Participant 112, female).

Counselling/professional emotional support was defined as the participants' awareness of and engagement in personal supportive counselling to manage the difficult emotions and experiences involved in going through the ASD diagnostic process. The participants reported finding significant value in engaging in counselling during the process. As one participant described:

> And well, I see a psychologist myself, and that has helped immensely, just because it is overwhelming, and it is a lot to take in, and just the type of personality I am, yeah, I dunno, I just – I'm sensitive too. I guess he, maybe, inherited that from me – super sensitive, but I also – my self-expectations are so high. And so, when given something like this, all I want to do is, like, know in an instant, so they've helped me realize, like, one day at a time, and you can see my house is covered in mantras and in strategies… (Participant 109, female).

Child's characteristics and qualities involved the personality traits, qualities, and characteristics of the participants' child, as well as the other extenuating circumstances within which the child was functioning. In this category, the participants spoke about the strengths they saw in their child and how grateful they were for those particular traits. For example:

> he's happy, or but, you know, he – he's really active, or but he's, like, super fit, and, you know, he is actually really affectionate. Like, I'm so thankful that he doesn't have, like, touch aversion because that would be, like, be really hard for me (laughs) 'cause I am – I am a huge hugger, and so maybe I just like, forced it on him (laughs), but he, um – yeah, he seeks that, um, a lot, and that's a lot of him too is just, like, he's more of a seeker than an avoider, so, um, so it's – it's a little bit easier for me (Participant 116, female).

Hindering CI Categories

Table 5

Part II: Categories of Critical Incidents that were Perceived to Hinder Family Resilience

Category	PA	IN	%
Time pressures	8	8	**67**
Managing feedback and expectations of others	7	14	**58**
Managing personal and family stress	7	13	**58**
Watching child struggle with assessment tasks	5	6	**42**
Identification of child's weaknesses	3	4	**25**
Changes to typical family routines	3	4	**25**

Note. Participation rate > 25% are in boldface. PA = # of participants (N=12); IN = # of incidents (N=274); % = participation rate percentage.

Time pressures was the CI category endorsed by the most participants. This category was defined as the participants difficulty balancing the importance of quick and early intervention and the unavoidable waitlists for appointments and services. More specifically, participants reported feeling pressure to complete things as quickly as possible and feeling as though there was little or no support for the caregivers while they were on the waitlist. One participant described the following:

> ...time does seem to be precious because there's that whole the sooner and earlier you act, um, with autism, you may be able to, um, prevent some problems – be a bit more preventative in the treatment – and catch them before they happen (Participant 101, female).

Managing feedback and expectations of others involved receiving unwanted or unhelpful feedback and reactions from family, friends, acquaintances, and strangers regarding their child's difficulties, the diagnosis, or the participants' parenting choices. These CIs included the participants experiences with feeling judged or unsupported by those around them. Additionally, some participants felt blamed for the diagnosis or a need to defend the diagnosis to others. For example:

> …the 'you're mommy coddling; that's why he doesn't do these things', um, so it was more along the lines of, it's – insinuating it's my fault, the way he is, because of the way I mother him, ultimately, um, would lead to bitterness… (Participant 101, female).

Managing personal and family stress included the everyday stressors of managing a child with developmental concerns, the stressful nature of managing multiple appointments, and the impact of stress on family relationships. The participants reflected on the increase in stress in all areas of their life while going through the ASD process. They stated that the appointments were stressful on the caregivers, as well as the siblings of the child going through the diagnostic process. It was recollected that feeling like they were alone in navigating the process exacerbated the participants' feelings of stress. For example, one participant stated:

> Like, I put a lot of pressure on myself, which I think did not make me feel all that resilient, you know, and I look back now and I think, like, that was so hard, you know, and when I – you know, meeting with all those therapists, and thinking, like, oh, you're putting a lot of pressure on yourself, whose not a trained therapist in anything, and yet, there are now, like, six therapists and one aid and a pediatrician, and all of these people who are specialists in that area, right, but you don't go and see anyone else, you know, and you're sort of – things are taking time, and it's easy not to talk about a time line, but being, like, oh, you know, you're waiting, right, and so it's hard to not know, or, as a parent, to be the only one, and you feel like what if, like, what I'm doing is making her talk or not talk? (Participant 112, female).

Watching child struggle with assessment tasks was defined as the participants' emotional difficulties in watching their child become frustrated or struggle with the difficult assessment tasks. The participants spoke about their frustration in seeing the inflexibility of the assessment tasks to make things easier for their child. They stated that watching their child become stressed or frustrated was very difficult for them. One participant described the following:

> He couldn't even do the first question. That was really hard – to sit there and watch him struggle; but equally, when he was then given the puzzles, and he was like a whiz, and he was able to do the more advanced ones, that was like – that felt good. But watching him struggle, um…was – made you feel, like, bad, and, like, if he's struggling, the whole family's going to struggle (Participant 101, female).

Identification of child's weaknesses was defined as the participants needing to communicate their child's weaknesses to the assessment team, as well as the team communicating the child's weaknesses to the participants during the assessment debrief session.

The participants reflected on the difficulty they had in discussing how their child was struggling and, at times, disagreeing with the areas that their child demonstrated weaknesses in the assessment. For example:

> one parent may not feel that the child is lacking in that area, and then you look at a written report, and the teacher is saying that he is, and one parent might think it is, so it's a little bit – it's almost like a little bit conflicting because you – as much as you want to be on the same page, you may not see the same things. Like, as parents, we may not see the same things as the teacher sees (Participant 106, female).

Changes to typical family routines was defined as the need to cancel or modify one's typical routines, activities, and hobbies because of the child's difficulties. The participants highlighted the need to make sacrifices, avoid certain social situations, and to manage the negative consequences of these changes. One participant stated:

> So, like, it's like, okay, we can't go to that, those birthday parties; we're not inviting him to his birthday party. Like, I'm not putting my son through that, so it puts a rift, you know (Participant 109, female).

Wish List Items

Table 6

Part II: Categories of Factors that were Believed to have Facilitated Family Resilience

Category	PA	IN	%
Information and knowledge about ASD	2	2	17
Support by family and friends	1	2	8

Note. Participation rate > 25% are in boldface. PA = # of participants (N=12); IN = # of incidents (N=274); % = participation rate percentage.

Many participants did not identify any specific things they believed they could do or change to make a positive difference in helping their own family resilience. The majority of the WLs were directed toward professional changes (see Part I of this study) because they felt the professionals had more power to make those changes. Nevertheless, two participants spoke about the need for more information and knowledge about ASD. They stated that they were often asked questions about unique subgroups within the ASD community (i.e., high functioning children, issues around gender, etc.) and they felt they did not have enough knowledge to answer the questions adequately. Therefore, there was a desire by these participants to increase their own knowledge to better advocate and educate within their communities.

Discussion

To date, there has been much literature dedicated to the exploration and evaluation of resilience in families. This literature is helpful for families with children with ASD, but because of the unique circumstances faced by families in the presence of ASD, their experience of resilience and the factors that promote it may look somewhat different. Caregivers play an important role in promoting and enhancing family resilience (Beeghly & Tronick, 2011). They use internal and external supports to empower themselves and their family during difficult and trying circumstances (Bayat, 2007). Despite the continued evidence of the importance of family resilience in healthy overall functioning (Harris & Glasberg, 2003), little research to date provides specific recommendations from families regarding the promotion of family resilience during the ASD diagnosis assessment. The following discussion reviews the personal, situational, and systemic factors that caregivers identified as contributing to their family resilience during the ASD diagnosis process. Ideally, caregivers of children being considered for an ASD diagnosis will use the following information to prepare, promote, and enhance their own family resilience.

External Influences

External influences can either promote or challenge family resilience. By being aware of the presence of these influences – seeking out those that enhance and protecting one's self against those that challenge – caregivers can approach the experience of having a child diagnosed with ASD feeling prepared and ready to assist their family in feeling as resilient as possible.

Resilience-enhancing influences. The role of social support in enhancing family resilience is well-established (Brobst et al., 2009; Carter, Martinez-Pedraza, & Gray, 2009; Ekas et al., 2010; Hall & Graff, 2011; Tobing & Glenwick, 2007). The participants in this study echoed what was found in the literature and highlighted formal and informal social support as being pertinent to their feeling family resilience (Boyd, 2002; Ekas et al, 2010). The most endorsed helping CI was the emotional support from family and friends, followed by access to community- and internet-based support groups. The participants found comfort and strength in sharing their experiences with others who were familiar with what they were going through. The participants identified feeling supported by partners, peers, parents, grandparents, and siblings. They reported feeling accepted and normalized when sharing their frustrations, worries, and struggles. Another formal support that was found in the literature and endorsed by the participants, was accessing professional counselling services (Bitsika & Sharpley, 2000). The participants reported feeling supported, grounded, and recharged through their therapeutic work which reportedly made them feel more equipped and prepared to handle the stress associated with the diagnosis process. Although it can be difficult for caregivers of a child being diagnosed with ASD to justify taking time for themselves and their own self-care management, the value of it and positive impact on the overall family's resilience makes it worthwhile.

Resilience-challenging influences. Just as there are external supports that can help a family feel more family resilience, there are external factors that can challenge or hinder a family's feelings of resilience. Time pressures were reported as having a significant negative impact on family resilience. Caregivers reported feeling constantly torn between knowing the importance of early intervention and the reality of waitlists for diagnosis and supports. The delays between the caregivers' first suspicions, assessment, diagnosis, and access to services have several negative impacts on family functioning; such as, decreased parent adaptation, coping ability, dissatisfaction, increased stress, blame, and doubt (Baird, McConachie, & Scrutton, 2000; Howlin & Moore, 1997). Although waitlists and delays are largely out of the caregivers' hands, caregivers can be prepared for time pressures by expecting them, speaking with their professionals about them, and advocating for their child's access to services while waiting for the diagnosis.

Receiving certain information from others was also identified as challenging family resilience. Participants endorsed two specific kinds of information that they found to be more difficult to hear. First, the identification of their child's weaknesses and second negative feedback from friends and family. Hearing reports of their child's weaknesses by the professionals, in the assessment report, and even by themselves while completing the parent interview portion of the assessment was difficult, uncomfortable, and stressful. This impact is directly related to the role of positive cognition in promoting family resilience (Bekhet et al., 2012a). Families that need to focus on negative attributes and experiences are more likely to feel less resilient. Similarly, feeling a lack of support from friends and family, needing to defend the diagnosis, or manage other people's accusations and criticisms burdens the caregiver and limits his or her ability to maintain positive, hopeful, and optimistic thinking. Caregivers have very little control over the type of feedback they receive from those around them. Nevertheless, by actively pursuing relationships with those who will be supportive and uplifting and choosing to limit interactions with those who tend to provide negative feedback can help promote a sense of family resilience.

Finally, two participants identified the need for more specific information about ASD and their child's presentation of ASD (i.e., high functioning ASD, gender difference, comparisons between children with ASD and neurotypical children). They felt that by having this more specific information they would feel better equipped to answer questions regarding their child and more confident in their ability to advocate for their child. Acquiring relevant information is an important step in the resilience building process (Kandel & Merrick, 2007). Caregivers can prepare for this influence by seeking out and establishing a network of credible sources and resources about ASD. This does not mean they can be perfectly prepared for any question they may be faced with, but by having the confidence in their ability to know where to look to find the information, they can feel more optimistic and resilient in their pursuit of that information.

Internal Influences

Parental personality, characteristics, past experiences, and attitudes can also have a significant impact on family resilience (Kiplinger & Browne, 2014). By being aware of the characteristics within one's self that may help or hinder feelings of family resilience, caregivers can actively engage with themselves in healing necessary hurts, managing stressors, bolster positive outlooks, and engage in practices that promote personal well-being.

Resilience-enhancing influences. Parental attitude and outlook on life was the most endorsed internal resilience factor. The participants highlight characteristics of determination, optimism, faith, and confidence in their ability to parent, advocate, and support their child with ASD. Participants identified the role of spirituality and religion, meaning making, and a positive outlook (Walsh, 2003) in their family resilience and reported a sense of purpose and confidence in their future. Part of the process of maintaining a positive outlook is the deliberate and intentional identification of each family members strengths and family contributions (Patterson, 2002), including the child with ASD. The participants reported a conscious recognition of the positive qualities and characteristics of their child with ASD and expressed gratitude about the presence of that strength in their child's functioning. By keeping these reminders at the front of their awareness, the participants were able to focus on hope and optimism which positively influence their family resilience.

Another important internal factor that enhanced feelings of family resilience was past experiences with resilience. Participants reported feeling more equipped to face the challenges ahead because they had evidence of their family's ability to do so in their past. Although past experiences of resilience do not guarantee present resilience (Patterson, 2002), understanding the tools and strategies the family successfully used in the past can provide important insight into how to promote resilience and healthy functioning in the present (Becvar, 2013). Caregivers who have experienced, supported, and thrived in their family during a past crisis or trauma, will feel more confident and competent, which is directly linked to feeling resilience (Masten, 2014).

Resilience-challenging influences. Similar to external resilience-challenging factors, there are factors within each caregiver that can challenge feelings of family resilience. For example, family stress, marital dissatisfaction or conflict, and mental health related concerns can all negatively influence family resilience (Brobst et al., 2009; Hartley et al., 2011; Higgins et al., 2005). Contributing to the increase in stress caused by these factors is the difficulty caregivers of children with ASD have in maintaining hobbies, self-care routines, and routine (Fiese, 2006; Glass, 2001; Karst & Van Hecke, 2012; Smith et al., 2010). The importance of establishing new routines as early as possible is evidenced in the literature (Fiese, 2006). Families with a child with ASD must deal with a wide range of practical stressors. Stressors related to time, finances, support, educational needs, medical care access, advocacy, limited time for work, and the constant presence of support workers in the home (Lord & Bishop, 2010; Morrison, Sansosti, & Hadley, 2009; Pakenham, Samios, & Sofronoff, 2005; Woodgate, Ateah, & Secco, 2008). By attending to these personal and family stressors quickly and effectively (either on their own or with professional help) caregivers will protect themselves from their negative impact on family resilience.

Finally, the participants highlighted the emotional impact of watching their child struggle with tasks during the assessment appointments. They stated that they felt saddened and less resilient because of the clear and obvious stress the appointment was causing the child. Although the connection between observing a child's struggle and family resilience has not been established in the literature, it does align well with evidence that suggests symptom severity, negative emotionality, and stress are risk factors to family resilience (Bekhet et al., 2012b). Again, the likelihood that a child will struggle with some tasks during an ASD diagnostic assessment is quite high; therefore, it is unreasonable to expect caregivers to avoid this influence on family resilience. Nevertheless, by having an awareness about what to expect during the diagnostic appointments and being prepared for the child's periods of frustration and struggle, caregivers can arm themselves against the negative consequences of feeling surprised or caught off-guard by the internal resilience-challenging influences.

Limitations and Future Research

The present study offers a unique look into the caregivers' promotion of family resilience during the ASD diagnostic assessment process. As an exploratory study with a small number of participants, there are a few limitations that need to be discussed. First, participants who volunteer to participate in a family resilience study are likely individuals who already experience a high degree of resilience. It is likely, therefore, that they possessed a unique ability to identify resilience building factors from their own personalities and contexts. Second, the research and its findings are limited to the geographical region of Alberta, Canada and therefore have limited transferability to other regions. Finally, there was a research assumption made that the female primary caregiver can speak to the resilience experiences of the whole family which may limit the application of this research to families with male primary caregivers and single caregiver homes.

This study demonstrates the valuable role that caregivers play in promoting family resilience in the presence of an ASD diagnosis process. Several important helping and hindering categories were identified that caregivers may find useful in maintaining and facilitating their own family resilience. Future research should aim to better understand family resilience from multiple perspectives (i.e., caregivers, siblings, and the child with ASD), which will create a more holistic and comprehensive view of family resilience during the diagnosis of a child with ASD. Additionally, further exploration of the application of these helping and hindering factors to families from diverse cultural backgrounds, multi-generational family homes, and other geographical regions is needed. Finally, the evaluation of the benefits of caregivers having this knowledge prior to or at the beginning of the assessment process will help to establish the credibility and value of this research. By continuing this research, caregivers will be better equipped to maintain and promote family resilience during the various difficult, stressful, and taxing experiences involved in raising a child with ASD.

References

Baird, G., McConachie, H., & Scrutton, D. (2000). Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood, 83*, 475-480. http://dx.doi.org/10.1136/adc.83.6.475

Barker, E. T., Mailick, M. R., & Smith, L. E. (2014). Chronic parenting stress in mothers of adolescents and adults with autism: Vulnerability and resilience. In V. B. Patel, V. R. Preedy, & C. R. Martin (Eds.). *Comprehensive Guide to Autism* (pp. 207-222) doi: 10.1007/978-1-4614-4788-7_9

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*, 702-714. doi: 10.1111/j.1365-2788.2007.00960.x

Becvar, D. S. (Ed.). (2013). *Handbook of family resilience.* New York, NY: Springer.

Beeghly, M. & Tronick, E. (2011). Early resilience in the context of parent-infant relationships: A social developmental perspective. *Current Problems in Pediatric and Adolescent Health Care, 41*, 197-201. doi: 10.1016/j.cppeds.2011.02.005

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012a). Effects on resilience of caregivers of persons with autism spectrum disorder: The role of positive cognitions. *Journal of the American Psychiatric Nurses Association, 18*, 337-344. doi: 10.1177/1078390312467056

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012b). Resilience in family members of persons with autism spectrum disorder: A review of the literature. *Issues in Mental Health Nursing, 33*, 650-656. doi: 10.3109/01612840.2012.671441

Benson, P. R. & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders, 39*, 350-362. doi: 10.1007/s10803-008-0632-0

Bitsika, V., & Sharpley, C. G. (2000). Development and testing of the effects of support groups on the well-being of parents of children with autism-II: Specific stress management techniques. *Journal of Applied Health Behaviour, 2*(1), 8-15.

Bitsika, V., Sharpley, C. G., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal of Developmental Physical Disabilities, 25*, 533-543. doi: 10.1007/s10882-013-9333-5

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*, 208-215. doi: 10/1177/10883576020170040301

Brobst, J. B., Clopton, J. R., & Hedrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24*, 38-49. doi: 10.1177/1088357608322699

Butterfield, L.D., Borgen, W.A., Amundson, N.E., & Maglio, A.S.T. (2005). Fifty years of the critical incident technique: 1954-2004 and beyond. *Qualitative Research, 5*, 475-497.

Butterfield, L. D., Borgen, W. A., Maglio, A. T., & Amundson, N. E. (2009). Using the enhanced critical incident technique in counselling psychology research. *Canadian Journal of Counselling, 43*, 265-282.

Carter, A. S., Martinez-Pedraza, F. D. L., & Gray, S. A. O. (2009). Stability and individual change in depressive symptoms among mothers raising young children with ASD:

Maternal and child correlates. *Journal of Clinical Psychology, 65*, 1270-1280. doi: 10.1002/jclp.20634

Ekas, N. V. & Whitman, T. L. (2010). Autism symptom topography and maternal socioemotional functioning. *American Journal on Intellectual and Developmental Disabilities, 115*(3), 234-249. doi: 10.1352/1944-7558-115.3.234

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 1274-1284. doi: 10.1007/s10803-010-0986.y

Ekas, N. V., Whitman, T. L., & Shivers, C. (2009). Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 39*, 706-719. doi: 10.1007/s10803-008-0673-4

El-Ghoroury, N. H. (2012). Resilience and the narratives of parents of adults with autism spectrum disorders. *Narrative Inquiry in Bioethics, 2*, 189-197. doi: 10.1353/nib.2012.0056

Evans, A. (2010). *Parents' responses to their child's diagnosis of autism spectrum disorder (ASD)* (Doctoral dissertation). Retrieved from http://eprints.soton.ac.uk/172757/1.hasCoversheetVersion/Thesis_-_Amber_Evans.pdf

Fiese, B. H. (2006). *Family routines and rituals.* New Haven, CT: Yale University Press.

Glass, P. W. (2001). *Autism and the family: A qualitative perspective* (Doctoral dissertation, Virginia Polytechnic Institute and State University). Retrieved from http://www.researchgate.net/profile/Marilyn_Lichtman/publication/253191008_AUTISM_AND_THE_FAMILY_A_QUALITATIVE_PERSPECTIVE/links/02e7e52a758983b89c000000.pdf

Gray, D. E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research, 50*, 970-976. doi: 10.1111/j.1365-2788.2006.00933.x

Hall, H. R. & Graff, J. C. (2011). The relationships among adaptive behaviours of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing, 34*, 4-25. doi: 10.31109/0146-862.2011.555270

Hartley, S. L., Barker, E. T., Seltzer, M. M., Greenberg, J. S., & Floyd, F. J. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal on Intellectual and Developmental Disabilities, 116*, 81-95. doi: 10.1352/1944-7558-116.1.81

Higgins, D., Bailey, S., & Pearce, J. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism, 9*, 125-137. doi: 10.1177/1362361305051403

Howling, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 parents in the UK. *Autism: International Journal of Research and Practice, 1*, 135-162. https://doi.org/10.1177/1362361397012003

Kandel, I., & Merrick, J. (2007). The child with a disability: Parental acceptance, management and coping. *The Scientific World Journal, 7*, 1799-1809. doi: 10.1100/tsw.2007.265

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of Autism Spectrum Disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychological Review, 15*, 247-277. doi: 10.1007/s10567-012-0119-6

Kiplinger, V. L., & Browne, C. H. (2014). *Parents' assessment of protective factors: User's guide and technical report*. New York, NY: Center for the Study of Social Policy.

Kuhn, J. C., & Carter, A. S., (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry, 76*, 564-575. doi: 10.1037/0002-9432.76.4.564

Lord, C., & Bishop, S. L. (2010). Autism spectrum disorders: Diagnosis, prevalence, and services for children and families. *Society for Research in Child Development, 24*, 1-21.

Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast Asian parents raising a child with autism: A qualitative investigation of coping styles. *Journal of School Nursing, 25*, 222-229. doi: 10.1177/1059840509334365

Masten, A. S. (2014). *Ordinary magic: Resilience in development.* New York, NY: The Guilford Press.

Morrison, J. Q., Sansosti, F. J., & Hadley, W. M. (2009). Parent perceptions of the anticipated needs and expectations for support for their college-bound students with Asperger's' syndrome. *Journal of Postsecondary Education and Disability, 22*, 78-87.

Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment. *Autism, 9*, 181-212. doi: 10.1177/1362361305049033

Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family, 64*, 349-360. doi: 10.1111/j.1741-3737.2002.00349.x

Siman-Tov, A. & Kaniel, S. (2011). Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model. *Journal of Autism and Developmental Disorders, 41*, 879-890. doi: 10.1007/s10803-010-112-x

Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 167-178. doi: 10.1007/s10803-009-0844-y

Terry, D. & Hynes, G. (1998). Adjustment to a low-control situation: Reexamining the role of coping responses. *Journal of Personality and Social Psychology, 74*, 1078-1092. doi: 10.1037/0022-3514.74.4.1078

Tobing, L. E. & Glenwick, D. S. (2007). Predictors and moderators of psychological distress in mothers of children with pervasive development disorders. *Journal of Family Social Work, 10*, 1-22. doi: 10.1300/J039v10n04_01

Van Breda, A. D. (2001). *Resilience theory: A literature review.* Pretoria, South Africa: South African Military Health Service.

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*, 1-18. doi: 10.1111/j.1545-5300.2003.00001.x

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative Health Research, 18*, 1075-1083. doi: 10.1177/1049732308320112

CHAPTER FIVE: General Discussion and Conclusions

The deliberate and intentional exploration into the positive characteristics, strengths, and resources of individuals with ASD and their families is an important and necessary next step in the evolution of ASD-related research. Specifically, a focus on deepening the understanding of how these families thrive, how they experience positive emotions, and how they can come to lead personally fulfilling and satisfying lives is needed. By using the construct of resilience as an entry point, the positive psychology research community can use this already well established ASD-related factor (Gold, 2017; Halstead, Ekas, Hastings, & Griffith, 2018; Kaboski, McDonnel, & Valentino, 2017) to further develop a balance in the ASD research community. Positive psychology researchers can expand on the developed ASD-resilience literature base to include: (a) identifying ways to promote and enhance resilience—possibly through the use of positive emotions; and, (b) connecting the promotion of resilience to long-term positive life experiences—such as, increased quality of life, life satisfaction, and life fulfillment (Cohn, Fredrickson, Brown, Mikels, & Conway, 2009).

After a call to action to all ASD researchers, the study is the first step in the process of identifying specific factors that enhance or harm the experience of resilience in families of children with ASD during the ASD diagnostic process. By dividing the findings into factors relevant to professionals and factors relevant to families, the value of a systemic approach is evident. It is not solely the professional's responsibility to promote resilience in families and it is not solely the responsibility of parents/caregivers. Rather, professionals and families can work together to create a family-specific plan for maintaining resilience, optimism, and hope during and following the formal diagnosis of a child with ASD. This study is a small but meaningful step in a larger research goal of better understanding how resilience-promotion can be used to prepare families for their parenting journeys.

Key Factors for Professionals

Professionals play an important role in helping families of individuals with ASD navigate ASD-specific situations and experiences. When professionals provide necessary support, caregivers are more likely to engage in specific intervention strategies, treatment plans, and to attend follow up appointments (Zand, Braddock, Baig, Deasy, & Maxim, 2013). Support can take many different forms, but encouraging caregiver self-efficacy, self-sufficiency, self-management, personal agency, and problem solving are effective support strategies (Mazzucchelli & Sanders, 2012). The caregivers in this study identified recommendations in three specific domains: (a) practical and resource-based recommendations; (b) emotional support recommendations; and, (c) systemic recommendations.

Practical and Resource-Based Recommendations. These are the key factors that professionals can consider when planning their process for conducting ASD diagnostic assessments. First, informational support is seen as valuable both as a way to provide emotional reassurance to caregivers, but also in providing specific step-by-step advice about how to best prepare and support their child (Aymanns, Sigrun, & Klaur, 1995; Donnellan, Bennett, & Soulsby, 2015; Pinkerton & Dolan, 2007; Williams, Alexander, Bolsover, & Bakke, 2008). Second, formal and informal peer and family support by others who have been through similar experiences is a valuable resilience-building tool (Becvar, 2013; Jones, Killett, & Mioshi, 2018; McCrimmon & Montgomery, 2014). Third, the caregivers noted that having a multidisciplinary team (Centre for Disease Control and Prevention, 2001) increased their confidence in the professionals (MacVicar, Kirkpatrick, Humphrey, & Forbes-McKay, 2015) and assisted them in accepting the accuracy of the diagnosis (Lietz, 2007). Additionally, having easy (Hogden, Greenfield, Nugus, & Kiernan, 2012) and open (Lietz, 2007; Lin, Rong, & Lee, 2013; Stokar, Baum, Plishchke, & Ziv, 2014) communication with the assessment team is important to the families and they reported that a lack of communication or availability had a significant negative impact on their resilience. Finally, maintaining jargon-free (Cicchetti & Toth, 1993; Huston, 1994; Knitzer, 1996; Luthar, 1999; Luthar & Cicchetti, 2000), compassionate (Cunningham, Morgan, McGucken, 1984; Lingham & Newton, 1996), child-specific (Brenner, 2003), and timely (Baird, McConachie, & Scrutton, 2000; Nursey, Rhode, & Farmer, 1991) communication and reports can help caregivers feel supported and respected during the debrief process.

Emotional Support Recommendations. Unsurprisingly, the participants in this study valued the emotional support offered by the professionals they encountered. The participants valued genuine concern, acceptance, empathy, warmth, and compassion (Ekas, Lickenbrock, & Whitman, 2010; Lin et al., 2013; Luthar & Cicchetti, 2000), as well as professional affirmation of parenting skills (Kiplinger & Browne, 2014) and messages of realistic hope (Faso, Neal-Beevers, & Carlson, 2012; Zand et al., 2013). Of equal importance, is the way professionals demonstrate support, care, patience, and kindness when interacting with their children (Bowers, 2015).

Systemic Recommendations. Finally, the caregivers in this study had specific systemic recommendations that contributed to their feelings of resilience. Barriers to services were found to be especially trying for these families and had significant influence on their sense of control, strength, and efficacy in navigating their child's care (Taylor & Warren, 2012).

Key Factors for Families

In the same way professionals can play an important role in promoting resilience for families of individuals with ASD, so too can caregivers (Beeghly & Tronick, 2011). By fostering specific protective factors in these families, caregivers are able to be more resourceful, optimistic, and have an increased sense of self efficacy (Bekhet, Johnson, & Zauszniewski, 2012a; Ekas et al., 2010; Siman-Tov & Kaniel, 2011). In the study, caregivers identified external and internal influences on their resilience.

External Influences. External influences are contributors that came from outside of the caregiver's immediate family. Social support (Boyd, 2002; Ekas et al., 2010) from extended family, friends, and formal support groups and the sharing of their experiences allowed the participants to feel comforted and strengthened. Professional counselling support also increased caregiver resilience by helping them to feel supported, grounded, and energized (Bitsika & Sharpley, 2000). Conversely, negative feedback from others was a significant challenge to resilience. Hearing about their child's weaknesses and areas of difficulty, made it difficult for caregivers to remain positive and therefore resilient (Bekhet et all, 2012a). Additionally, hearing negative feedback from others, needing to justify the diagnosis, and managing criticism from others was identified as being harmful to their family resilience. Finally, feeling uninformed or unable to answer specific questions about ASD or their child, caused some caregivers to feel less resilience and they felt that more specific and relevant information about their child's diagnosis would have been helpful (Kandel & Merrick, 2007).

Internal Influences. Internal influences on resilience included factors that were found within the caregivers themselves. The caregivers identified attitude, determination, strength-focus (Patterson, 2002), and confidence in their parenting ability, advocacy, and supports

(Kiplinger & Browne, 2014), as well as spirituality/religion (Walsh, 2003) as being integral to their experiences of resilience. Additionally, several caregivers reflected on the importance of drawing on their knowledge of previous experiences of resilience to help them remain resilient in the present (Becvar, 2013; Masten, 2014). The maintenance of routines, self-care, and leisure activities, as well as the adoption of new routines, can also increase a families' ability to remain resilient during times of trial (Fiese, 2006; Glass, 2001; Karst & Van Hecke, 2012; Smith et al., 2010). Finally, the effective management of the myriad of stressors (i.e., time, finances, education, medical care access, etc.) as well as the emotional difficulty of watching a child struggle with daily tasks is an important part of remaining resilient (Bekhet Johnson, & Zauszniewski, 2012b; Lord & Bishop, 2010; Morrison, Sansosti, & Hadley, 2009; Pakenham, Samios, & Sofronoff, 2005; Woodgate, Ateah, & Secco, 2008).

Relevance for Counselling Psychologists

The three components of this paper (the researcher call to action and the two empirical articles) are relevant to counselling psychologists in two important ways. First, within Alberta, there is an increasing number of counselling psychologists becoming involved in ASD research, becoming trained in ASD assessment, and becoming dedicated to ASD advocacy. And, second, counselling psychologists may have the opportunity to work with individuals with ASD and their caregivers and loved ones as they engage in the diagnostic process and adjust to life thereafter.

The knowledge added by this study has both research and practical implications about future work with ASD populations. By adopting a positive psychology framework, researchers and practitioners can create and use a balanced perspective of this unique population; supporting them in creating a full and satisfying life for themselves and their families.

References

Aymanns, P., Sigrun, H., & Klaur, T. (1995). Family support and coping with cancer: Some determinants and adaptive correlates. *British Journal of Social Psychology, 34*, 107-124. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.2044-8309.1995.tb01051.x

Baird, G., McConachie, H., & Scrutton, D. (2000). Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood, 83*, 475-480. http://dx.doi.org/10.1136/adc.83.6.475

Becvar, D. S. (Ed.). (2013). *Handbook of family resilience.* New York, NY: Springer.

Beeghly, M. & Tronick, E. (2011). Early resilience in the context of parent-infant relationships: A social developmental perspective. *Current Problems in Pediatric and Adolescent Health Care, 41*, 197-201. doi: 10.1016/j.cppeds.2011.02.005

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012a). Effects on resilience of caregivers of persons with autism spectrum disorder: The role of positive cognitions. *Journal of the American Psychiatric Nurses Association, 18*, 337-344. doi: 10.1177/10788390312467056

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012b). Resilience in family members of persons with autism spectrum disorder: A review of the literature. *Issues in Mental Health Nursing, 33*, 650-656. doi: 10.3109/01612840.2012.671441

Bitsika, V., & Sharpley, C. G. (2000). Development and testing of the effects of support groups on the well-being of parents of children with autism-II: Specific stress management techniques. *Journal of Applied Health Behaviour, 2*(1), 8-15.

Bowers, A. (2015). *The experience of mothers and clinicians in the assessment of autism spectrum disorder* (Master's Thesis). Retrieved from https://open.library.ubc.ca/cIRcle/collections/ubctheses/24/items/1.0166483#downloadfiles

Brenner, E. (2003). Consumer-focused psychological assessment. *Professional psychology, 34*, 240-247. doi: 10.1037/0735-7028.34.3.240

Center for Disease Control and Prevention. (2001). Frequently asked questions about autism. Atlanta, GA: Center for Disease Control.

Cicchetti, D., & Toth, S. L. (Eds.). (1993). *Child abuse, child development, and social policy.* Norwood, NJ: Ablex.

Cohn, M. A., Fredrickson, B. L., Brown, S. L., Mikels, J. A., & Conway, A. M. (2009). Happiness unpacked: Positive emotions increase life satisfaction by building resilience. *Emotion, 9*, 361-368. doi: 10.1037/a0015952

Cunningham, C. C., Morgan, P., & McGucken, R. B. (1984). Down's syndrome: Is dissatisfaction with disclosure of diagnosis inevitable? *Developmental Medicine and Child Neurology, 26*, 33-39. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.1469-8749.1984.tb04403.x

Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & Mental Health, 19*, 932-939. doi: 10.1080/13607863.2014.977771

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 1274-1284. doi: 10.1007/s10803-010-0986.y

Faso, D. J., Neal-Beevers, A. R., & Carlson, C. L. (2012). Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*, 288-297. http://dx.doi.org/10.1016/j.rasd.2012.08.014

Fiese, B. H. (2006). *Family routines and rituals.* New Haven, CT: Yale University Press.

Glass, P. W. (2001). *Autism and the family: A qualitative perspective* (Doctoral dissertation, Virginia Polytechnic Institute and State University). Retrieved from http://www.researchgate.net/profile/Marilyn_Lichtman/publication/253191008_AUTISM_AND_THE_FAMILY_A_QUALITATIVE_PERSPECTIVE/links/02e7e52a758983b89c000000.pdf

Gold, M. R. (2017). *Parent perceptions of the relation between resilience, autism, and sibling relationship quality* (Doctoral dissertation). Retrieved from ProQuest. (Order No. 10258912).

Halstead, E., Ekas, N., Hastings, R. P., & Griffith, G. M. (2018). Associations between resilience and the well-being of mothers of children with autism spectrum disorder and other developmental disabilities. *Journal of Autism and Developmental Disorders, 48*, 1108-1121. https://doi.org/10.1007/s10803-017-3447-z

Hogden, A., Greenfield, D., Nugus, P., & Kiernan, M. C. (2012). What influences patient decision-making in amyotrophic lateral sclerosis multidisciplinary care? A study of patient perspectives. *Patient Preference Adherence, 6*, 829-838. doi: 10.2147/PPA.S37851

Huston, A. C. (1994). Children in poverty: Designing research to affect policy. *Social Policy Report: Society for Research in Child Development, 8*(2), 1-12.

Jones, S. M., Killett, A., & Mioshi, E. (2018). What factors predict family caregivers' attendance at Dementia Cafés. *Journal of Alzheimer's Disease, 64*, 1337-1345. doi: 10.3233/JAD-180377

Kaboski, J., McDonnell, C. G., & Valentino, K. (2017). Resilience and autism spectrum disorder: Applying developmental psychopathology to optimal outcome. *Review Journal of Autism and Developmental Disorders, 4*, 175-189. https://doi.org/10.1007/s40489-017-0106-4

Kandel, I., & Merrick, J. (2007). The child with a disability: Parental acceptance, management and coping. *The Scientific World Journal, 7*, 1799-1809. doi: 10.1100/tsw.2007.265

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of Autism Spectrum Disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychological Review, 15*, 247-277. doi: 10.1007/s10567-012-0119-6

Kiplinger, V. L., & Browne, C. H. (2014). *Parents' assessment of protective factors: User's guide and technical report*. New York, NY: Center for the Study of Social Policy.

Knitzer, J. (1996). Children's mental health: Changing programs and policies. In E. F. Zigler, S. L. Kagan, & N. W., Hall (Eds.), *Children, families, and government: Preparing for the 21st century* (pp. 207-232). New York, NY: Cambridge University Press.

Lietz, C. A. (2007). Uncovering stories of family resilience: A mixed methods study of resilient families, part 2. *Families in Society: The Journal of Contemporary Social Services, 88*, 147-155. doi: 10.1606 / 1044-3894.3602

Lin, F., Rong, J., & Lee, T. (2013). Resilience among caregivers of children with chronic conditions: A concept analysis. *Journal of Multidisciplinary Healthcare, 6*, 323-333. http://dx.doi.org/10.2147/JMDH.S46830

Lingham, S., & Newton, R. (1996). *Right from the start: The way parents are told that their child has a disability.* London, UK: British Pediatric Association.

Lord, C., & Bishop, S. L. (2010). Autism spectrum disorders: Diagnosis, prevalence, and services for children and families. *Society for Research in Child Development, 24*, 1-21.

Luthar S. S. (1999). *Poverty and Children's adjustment.* Thousand Oaks, CA: Sage.

Luthar, S. S., & Cicchetti, D. (2000). The construct of resilience: Implications for interventions and social policies. *Development and Psychopathology, 12*(4), 857-885.

MacVicar, S., Kirkpatrick, P., Humphrey, T., & Forbes-McKay, K. E. (2015). Supporting breastfeeding establishment among socially disadvantaged women: A meta-synthesis. *Birth: Issues in Perinatal Care, 42*, 290-298. https://doi.org/10.1111/birt.12180

Masten, A. S. (2014). *Ordinary magic: Resilience in development.* New York, NY: The Guilford Press.

Mazzucchelli, T., & Sanders, M (2012). *Stepping stones triple P: A population approach to the promotion of competent parenting of children with disability*. Queensland, Australia: University of Queensland.

McCrimmon, A. W., & Montgomery, J. M. (2014). Resilience-based perspectives for Autism Spectrum Disorder. In S. Prince-Embury, & D. H. Saklofske (Eds.), *Resilience Interventions for Youth in Diverse Populations* (pp. 375-396). New York, NY: Springer Science+Business Media.

Morrison, J. Q., Sansosti, F. J., & Hadley, W. M. (2009). Parent perceptions of the anticipated needs and expectations for support for their college-bound students with Asperger's' syndrome. *Journal of Postsecondary Education and Disability, 22*, 78-87.

Nursey, A. D., Rhode, J. R., & Farmer, R. D. T. (1991). Ways of telling new parents about their child and his or her mental handicap: A comparison of doctor's and parents' views. *Journal of Mental Deficiency Research, 35*, 48-57. https://doi.org/10.1111/j.1365-2788.1991.tb01030.x

Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment. *Autism, 9*, 181-212. doi: 10.1177/1362361305049033

Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family, 64*, 349-360. doi: 10.1111/j.1741-3737.2002.00349.x

Pinkerton, J., & Dolan, P. (2007). Family support, social capital, resilience and adolescent coping. *Child and Family Social Work, 12*, 219-228. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.1365-2206.2007.00497.x

Siman-Tov, A. & Kaniel, S. (2011). Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model. *Journal of Autism and Developmental Disorders, 41*, 879-890. doi: 10.1007/s10803-010-112-x

Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 167-178. doi: 10.1007/s10803-009-0844-y

Stokar, Y. N., Baum, N. L., Plischke, A., & Ziv, Y. (2014). The key to resilience: A peer based youth leader training and support program. *Journal of Child and Adolescent Trauma, 7*, 111-120. doi: 10.1007/s40653-014-0016-x

Taylor, J. L., & Warren, Z. E. (2012). Maternal depressive symptoms following autism spectrum diagnosis. *Journal of Autism and Developmental Disorders, 42,* 1411-1418. doi: 10.1007/s10803-011-1375-x

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*, 1-18. doi: 10.1111/j.1545-5300.2003.00001.x

Williams, R., Alexander, D. A., Bolsover, D., & Bakke, F. K. (2008). Children, resilience and disasters: Recent evidence that should influence a model of psychosocial care. *Current Opinion in Psychiatry, 21*, 338-344. doi: 10.1097/YCO.0b013e328305b6e4

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative Health Research, 18*, 1075-1083. doi: 10.1177/1049732308320112

Zand, D. H., Braddock, B., Baig, W., Deasy, J., & Maxim, R. (2013). Role of pediatricians in fostering resilience in parents of children with autism spectrum disorder. *The Journal of Pediatrics, 163,* 1769-1771. doi: doi:10.1016/j.jpeds.2013.06.074

Bibliography

Alvord, M. K., & Grados, J. J. (2005). Enhancing resilience in children: A proactive approach. *American Psychological Association, 10*, 735-828. doi: http://dx.doi.org/10.1037/0735-7028.36.3.238

American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Washington, DC: Author.

Avramidis, E., Bayliss, P., & Burden, R. (2000). Student teachers' attitudes toward the inclusion of children with special educational needs in the ordinary school. *Teaching and Teacher Education, 16*, 277-293. doi: 10.1016/S0742-051X(99)00062-1

Aymanns, P., Sigrun, H., & Klaur, T. (1995). Family support and coping with cancer: Some determinants and adaptive correlates. *British Journal of Social Psychology, 34*, 107-124. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.2044-8309.1995.tb01051.x

Baird, G., McConachie, H., & Scrutton, D. (2000). Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Archives of Disease in Childhood, 83*, 475-480. http://dx.doi.org/10.1136/adc.83.6.475

Barker, E. T., Mailick, M. R., & Smith, L. E. (2014). Chronic parenting stress in mothers of adolescents and adults with autism: Vulnerability and resilience. In V. B. Patel, V. R. Preedy, & C. R. Martin (Eds.). *Comprehensive Guide to Autism* (pp. 207-222) doi: 10.1007/978-1-4614-4788-7_9

Baxter, C., Cummins, R., & Yiolitis, L. (2000). Parental stress attributed to family members with and without disability: A longitudinal study. *Journal of Intellectual and Developmental Disability, 25*, 105-118. doi: 10.1080/13269780050033526

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*, 702-714. doi: 10.1111/j.1365-2788.2007.00960.x

Becvar, D. S. (Ed.). (2013). *Handbook of family resilience.* New York, NY: Springer.

Beeghly, M. & Tronick, E. (2011). Early resilience in the context of parent-infant relationships: A social developmental perspective. *Current Problems in Pediatric and Adolescent Health Care, 41*, 197-201. doi: 10.1016/j.cppeds.2011.02.005

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012a). Effects on resilience of caregivers of persons with autism spectrum disorder: The role of positive cognitions. *Journal of the American Psychiatric Nurses Association, 18*, 337-344. doi: 10.1177/1078390312467056

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012b). Resilience in family members of persons with autism spectrum disorder: A review of the literature. *Issues in Mental Health Nursing, 33*, 650-656. doi: 10.3109/01612840.2012.671441

Benson, P. R. & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders, 39*, 350-362. doi: 10.1007/s10803-008-0632-0

Bitsika, V., & Sharpley, C. G. (2000). Development and testing of the effects of support groups on the well-being of parents of children with autism-II: Specific stress management techniques. *Journal of Applied Health Behaviour, 2*(1), 8-15.

Bitsika, V., Sharpley, C. G., & Bell, R. (2013). The buffering effect of resilience upon stress, anxiety and depression in parents of a child with an autism spectrum disorder. *Journal of Developmental Physical Disabilities, 25*, 533-543. doi: 10.1007/s10882-013-9333-5

Bornstein, M. H. (2001). Parenting: Science and practice. *Parenting: Science and Practice, 1*, 1-4. doi: 10.1080/15295192.2001.9681208

Bowers, A. (2015). *The experience of mothers and clinicians in the assessment of autism spectrum disorder* (Master's Thesis). Retrieved from https://open.library.ubc.ca/cIRcle/collections/ubctheses/24/items/1.0166483#downloadfiles

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*, 208-215. doi: 10/1177/10883576020170040301

Brenner, E. (2003). Consumer-focused psychological assessment. *Professional psychology, 34*, 240-247. doi: 10.1037/0735-7028.34.3.240

Brobst, J. B., Clopton, J. R., & Hedrick, S. S. (2009). Parenting children with autism spectrum disorders: The couple's relationship. *Focus on Autism and Other Developmental Disabilities, 24*, 38-49. doi: 10.1177/1088357608322699

Broderick, C. B. (1995). Understanding family process: Basics of family systems theory. Thousand Oaks, CA: Sage Publications.

Bruggink, A., Huisman, S., Vuijk, R., Kraaij, V., & Garnsefski, N. (2016). Cognitive emotion regulation, anxiety and depression in adults with autism spectrum disorder. *Research in Autism Spectrum Disorders, 22,* 34-44. http://dx.doi.org/10.1016/j.rasd.2015.11.003

Burgess, A. F., & Gutstein, S. E. (2007). Quality of life for people with autism: Raising the standard for evaluating successful outcomes. *Child and Adolescent Mental Health, 12*, 80-86. doi: 10.1111/j.1475-3588.2006.00432.x

Butterfield, L.D., Borgen, W.A., Amundson, N.E., & Maglio, A.S.T. (2005). Fifty years of the critical incident technique: 1954-2004 and beyond. *Qualitative Research, 5*, 475-497.

Butterfield, L. D., Borgen, W. A., Maglio, A. T., & Amundson, N. E. (2009). Using the enhanced critical incident technique in counselling psychology research. *Canadian Journal of Counselling, 43*, 265-282.

Capps, L., Nirmiya, N., & Sigman, M. (1992). Understanding of simply and complex emotions in non-retarded children with autism. *Journal of Child Psychology and Psychiatry, 33*, 1169-1182. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.1469-7610.1992.tb00936.x

Carter, A. S., Martinez-Pedraza, F. D. L., & Gray, S. A. O. (2009). Stability and individual change in depressive symptoms among mothers raising young children with ASD: Maternal and child correlates. *Journal of Clinical Psychology, 65*, 1270-1280. doi: 10.1002/jclp.20634

Castelli, F. (2005). Understanding emotions from standardized facial expressions in autism and normal development. *Autism, 9*, 428-449. https://doi-org.login.ezproxy.library.ualberta.ca/10.1177/1362361305056082

Centers for Disease Control and Prevention. (2014). *Autism spectrum disorder (ASD)*. Retrieved from http://www.cdc.gov/ncbddd/autism/data.html

Charney, D. S. (2004). Psychobiological mechanisms of resilience and vulnerability: Implications for successful adaptation to extreme stress. *American Journal of Psychiatry, 161*, 195-216. https://doi.org/10.1176/foc.2.3.368

Cicchetti, D. (2010). Resilience under conditions of extreme stress: A multilevel perspective. *World Psychiatry, 9*, 145-154. https://doi-org.login.ezproxy.library.ualberta.ca/10.1002/j.2051-5545.2010.tb00297.x

Cicchetti, D., & Toth, S. L. (Eds.). (1993). *Child abuse, child development, and social policy.* Norwood, NJ: Ablex.

Cicchetti, D., & Toth, S. L. (1998). The development of depression in children and adolescents. *American Psychologist, 53*(2)*,* 221-241.

Cohn, M. A., Fredrickson, B. L., Brown, S. L., Mikels, J. A., & Conway, A. M. (2009). Happiness unpacked: Positive emotions increase life satisfaction by building resilience. *Emotion, 9*, 361-368. doi: 10.1037/a0015952

Coleman, M. (1989). Young children with autism or autistic-like behavior. *Infants and Young Children, 1*, 22-31.

Combrinck-Graham, L. (1990). Developments in family systems theory and research. *Journal of the American Academy of Child and Adolescent Psychiatry, 29*, 501-512. doi: 10.1097/00004583-199007000-00001

Cummins, R. A. (1996). The domains of life satisfaction: An attempt to order chaos. *Social Indicators Research, 38*, 303-328. https://doi-org.login.ezproxy.library.ualberta.ca/10.1007/BF00292050

Cunningham, C. C., Morgan, P., & McGucken, R. B. (1984). Down’s syndrome: Is dissatisfaction with disclosure of diagnosis inevitable? *Developmental Medicine and Child Neurology, 26*, 33-39. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.1469-8749.1984.tb04403.x

Curry, J., Silva, S., Rohde, P., Ginsburg, G., Kratochvil, C., Simons, A., … March, J. (2011). Recovery and recurrence following treatment for adolescent major depression. *Archives of General Psychiatry, 68*, 263-269. doi:10.1001/archgenpsychiatry.2010.150

Diener, E., Emmons, R. A., Larsen, R. J., & Griffin, S. (1985). The satisfaction with life scale. *Journal of Personality Assessment, 49,* 71-75. 10.1207/ s15327752jpa4901_13

Diener, E., & Larsen, R. J. (1993). The experience of emotional well-being. In M. Lewis & J. M. Haviland (Eds.), *Handbook of emotions* (pp. 405-415). New York, NY: Guildford Press.

Donnellan, W. J., Bennett, K. M., & Soulsby, L. K. (2015). What are the factors that facilitate or hinder resilience in older spousal dementia carers? A qualitative study. *Aging & Mental Health, 19*, 932-939. doi: 10.1080/13607863.2014.977771

Doron, H., & Sharabany, A. (2013). Marital patterns among parents to autistic children. *Psychology, 4*, 445-453. doi: 10.4236/psych.2013.44063

Duckworth, A. L., Steen, T. A., & Seligman, M. E. P. (2005). Positive psychology in clinical practice. *Annual Review of Clinical Psychology, 1*, 629-651. doi: 10.1146/annurev.clinpsy.1.102803.144154

Dyson, L. L. (2003). Children with learning disabilities within the family context: A comparison with siblings in global self-concept, academic self-perception, and social competence. *Learning Disabilities Research & Practice, 18*, 1-9. doi:10.1111/1540-5826.00053

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 1274-1284. doi: 10.1007/s10803-010-0986.y

Ekas, N. V. & Whitman, T. L. (2010). Autism symptom topography and maternal socioemotional functioning. *American Journal on Intellectual and Developmental Disabilities, 115*(3), 234-249. doi: 10.1352/1944-7558-115.3.234

Ekas, N. V., Whitman, T. L., & Shivers, C. (2009). Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 39*, 706-719. doi: 10.1007/s10803-008-0673-4

El-Ghoroury, N. H. (2012). Resilience and the narratives of parents of adults with autism spectrum disorders. *Narrative Inquiry in Bioethics, 2*, 189-197. doi: 10.1353/nib.2012.0056

Evans, A. (2010). *Parents' responses to their child's diagnosis of autism spectrum disorder (ASD)* (Doctoral dissertation). Retrieved from http://eprints.soton.ac.uk/172757/1.hasCoversheetVersion/Thesis_-_Amber_Evans.pdf

Faso, D. J., Neal-Beevers, A. R., & Carlson, C. L. (2012). Vicarious futurity, hope, and well-being in parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 7*, 288-297. http://dx.doi.org/10.1016/j.rasd.2012.08.014

Fiese, B. H. (2006). *Family routines and rituals.* New Haven, CT: Yale University Press.

Finn, S. E. & Tonsager, M. E. (1992). Therapeutic effects of providing MMPI-2 test feedback to college students awaiting therapy. *Psychological Assessment, 4*, 278-287.

Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: Study of emotion and coping during three stages of a college examination. *Journal of Personality and Social Psychology, 48*, 150-170.

Fredrickson, B. L. (1998). What good are positive emotions? *Review of General Psychology, 2*, 300-319.

Fredrickson, B. L., Cohn, M. A., Coffey, K. A., Pek, J., Finkel, S. M. (2008). Open hearts build lives: Positive emotions, induced through loving-kindness meditation, build consequential personal resources. *Journal of Personality and Social Psychology, 95,* 1045-1062. doi: 10.1037/a0013262

Freedman, B. H., Kalb, L. G., Zaboltsky, B., & Stuart, E. A. (2012). Relationship status among parents of children with autism spectrum disorders: A population-based study. *Journal of Autism and Developmental Disorders, 42*, 539-548. doi: 10.1007/s10803-011-1269-y

Frijda, N. H. (1988). The laws of emotion. *American Psychologist, 43*, 349-358.

Gabriels, R. L., Hill, D. E., Pierce, R. A., Rogers, S. J., & Wehner, B. (2001). Predictors of treatment outcome in young children with autism: A retrospective study. *Autism, 5*, 407-429. doi: 10.1177/1362361301005004006

Gelso, C. & Fretz, B. (2001). *Counselling psychology* (2nd ed.). Belmont, CA: Wadsworth Group.

Gau, S. S., Chou, M., Chiang, H., Lee, J., Wong, C., Chou, W., & Wu, Y. (2011). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders, 6*, 263-270. doi: 10.1016/j.rasd.2011.05.007

Glass, P. W. (2001). *Autism and the family: A qualitative perspective* (Doctoral dissertation, Virginia Polytechnic Institute and State University). Retrieved from http://www.researchgate.net/profile/Marilyn_Lichtman/publication/253191008_AUTISM_AND_THE_FAMILY_A_QUALITATIVE_PERSPECTIVE/links/02e7e52a758983b89c000000.pdf

Gold, N. (1993). Depression and social adjustment in siblings of boys with autism. *Journal of Autism and Developmental Disorders, 23*, 147-163. doi: 10.1007/BF01066424

Gold, M. R. (2017). *Parent perceptions of the relation between resilience, autism, and sibling relationship quality* (Doctoral dissertation). Retrieved from ProQuest. (Order No. 10258912).

Gray, D. E. (2006). Coping over time: the parents of children with autism. *Journal of Intellectual Disability Research, 50*, 970-976. doi: 10.1111/j.1365-2788.2006.00933.x

Hall, H. R. & Graff, J. C. (2011). The relationships among adaptive behaviours of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing, 34*, 4-25. doi: 10.31109/0146-862.2011.555270

Halstead, E., Ekas, N., Hastings, R. P., & Griffith, G. M. (2018). Associations between resilience and the well-being of mothers of children with autism spectrum disorder and other developmental disabilities. *Journal of Autism and Developmental Disorders, 48*, 1108-1121. https://doi.org/10.1007/s10803-017-3447-z

Hamilton, L. (2000). *Facing autism: Giving parents reasons for hope and guidance for help.* Colorado Springs, CO: Water Brook Press.

Harris, S. & Glasberg, B. (2003). *Siblings of children with autism: A guide for families.* Bethesa, MD: Woodpine Press.

Hartley, S. L., Barker, E. T., Seltzer, M. M., Greenberg, J. S., & Floyd, F. J. (2011). Marital satisfaction and parenting experiences of mothers and fathers of adolescents and adults with autism. *American Journal on Intellectual and Developmental Disabilities, 116*, 81-95. doi: 10.1352/1944-7558-116.1.81

Higgins, D., Bailey, S., & Pearce, J. (2005). Factors associated with functioning style and coping strategies of families with a child with an autism spectrum disorder. *Autism, 9*, 125-137. doi: 10.1177/1362361305051403

Hinde, R. A., & Stevenson-Hinde, J. (1987). Interpersonal relationships and child development. *Developmental Review, 7*, 1-21. doi:10.1016/0273-2297(87)90002-5

Hinshaw, S. P., & Lee, S. S. (2003). Conduct and oppositional defiant disorders. In E. J. Mash & R. A. Barkley (Eds.), *Child psychopathology (2nd ed.)*. New York, NY: Guildford Press.

Hogden, A., Greenfield, D., Nugus, P., & Kiernan, M. C. (2012). What influences patient decision-making in amyotrophic lateral sclerosis multidisciplinary care? A study of patient perspectives. *Patient Preference Adherence, 6*, 829-838. doi: 10.2147/PPA.S37851

Howling, P., & Moore, A. (1997). Diagnosis in autism: A survey of over 1200 parents in the UK. *Autism: International Journal of Research and Practice, 1*, 135-162. https://doi.org/10.1177/1362361397012003

Huston, A. C. (1994). Children in poverty: Designing research to affect policy. *Social Policy Report: Society for Research in Child Development, 8*(2), 1-12.

Jones, S. M., Killett, A., & Mioshi, E. (2018). What factors predict family caregivers' attendance at Dementia Cafés. *Journal of Alzheimer's Disease, 64*, 1337-1345. doi: 10.3233/JAD-180377

Kaboski, J., McDonnell, C. G., & Valentino, K. (2017). Resilience and autism spectrum disorder: Applying developmental psychopathology to optimal outcome. *Review Journal of Autism and Developmental Disorders, 4*, 175-189. https://doi.org/10.1007/s40489-017-0106-4

Kandel, I., & Merrick, J. (2007). The child with a disability: Parental acceptance, management and coping. *The Scientific World Journal, 7*, 1799-1809. doi: 10.1100/tsw.2007.265

Kanner, L. (1943). Autistic disturbances of affective contact. *Nervous Child, 2*, 217-250.

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of Autism Spectrum Disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychological Review, 15*, 247-277. doi: 10.1007/s10567-012-0119-6

Kelly, A. B., Garnett, M. S., Attwood, T., & Peterson, C. (2008). Autism spectrum symptomatology in children: The impact of family and peer relationships. *Journal of Abnormal Child Psychology, 36*, 1069-1081. doi: 10.1007/s10802-008-9234-8

Kim, H., Doiron, K., Warren, M. A., & Donaldson, S. I. (2018). The international landscape of positive psychology research: A systematic review. *International Journal of Wellbeing, 8*, 50-70. Doi: 10.5502/ijw.v8il.651

Kiplinger, V. L., & Browne, C. H. (2014). *Parents' assessment of protective factors: User's guide and technical report*. New York, NY: Center for the Study of Social Policy.

Knitzer, J. (1996). Children's mental health: Changing programs and policies. In E. F. Zigler, S. L. Kagan, & N. W., Hall (Eds.), *Children, families, and government: Preparing for the 21st century* (pp. 207-232). New York, NY: Cambridge University Press.

Kuhn, J. C., & Carter, A. S., (2006). Maternal self-efficacy and associated parenting cognitions among mothers of children with autism. *American Journal of Orthopsychiatry, 76*, 564-575. doi: 10.1037/0002-9432.76.4.564

Lee, L., Harrington, R. A., Louie, B. B., & Newschaffer, C. J. (2008). Children with autism: Quality of life and parental concerns. *Journal of Autism and Developmental Disorders, 38*, 1147-1160. doi: 10.1007/s10803-007-0491-0

Lee, C. C. & Rodgers, R. A. (2009). Counselor advocacy: Affecting systemic change in the public arena. *Journal of Counseling & Development, 87*, 284-287. doi: 10.1002/j.1556-6678.2009.tb00108.x

Levenson, R. W. (1988). Emotion and the autonomic nervous system: A prospectus for research on autonomic specificity. In H. L. Wagner (Ed.), *Social psychophysiology and emotion: Theory and clinical applications* (pp. 17-42). Oxford, England: Wiley.

Li, F., Godinet, M. T., & Arnsberger, P. (2011). Protective factors among families with children at risk of maltreatment: Follow up to early school years. *Children and Youth Services Review, 33*, 139-148. doi: 10.1016/j.childyouth.2010.08.026

Lietz, C. A. (2007). Uncovering stories of family resilience: A mixed methods study of resilient families, part 2. *Families in Society: The Journal of Contemporary Social Services, 88*, 147-155. doi: 10.1606 / 1044-3894.3602

Lin, F., Rong, J., & Lee, T. (2013). Resilience among caregivers of children with chronic conditions: A concept analysis. *Journal of Multidisciplinary Healthcare, 6*, 323-333. http://dx.doi.org/10.2147/JMDH.S46830

Lingham, S., & Newton, R. (1996). *Right from the start: The way parents are told that their child has a disability.* London, UK: British Pediatric Association.

Lopez, S., Pedrotti, J. T., & Snyder, C. R. (2018). *Positive psychology: The scientific and practical explorations of human strengths* (4th ed.). Thousand Oaks, CA: Sage Publications Inc.

Lord, C., & Bishop, S. L. (2010). Autism spectrum disorders: Diagnosis, prevalence, and services for children and families. *Society for Research in Child Development, 24*, 1-21.

Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast Asian parents raising a child with autism: A qualitative investigation of coping styles. *Journal of School Nursing, 25*, 222-229. doi: 10.1177/1059840509334365

Luthar S. S. (1999). *Poverty and Children's adjustment.* Thousand Oaks, CA: Sage.

Luthar, S. S., & Cicchetti, D. (2000). The construct of resilience: Implications for interventions and social policies. *Development and Psychopathology, 12*(4), 857-885.

Luthar, S. S., Sawyer, J. A., & Brown, P. J. (2006). Conceptual issues in studies of resilience: Past, present, and future research. *Annals of the New York Academy of Sciences, 1094*, 105-115. doi: 10.1196/annals.1376.009

Lyubomirsky, S., King, L., & Diener, E. (2005). The benefits of frequent positive affect: Does happiness lead to success? *Psychological Bulletin, 131*, 803-855. doi: 10.1037/0033-2909.131.6.803

Maccoby, E. E., & Martin, J. A. (1983). Socialization in the context of the family: Parent-child interaction. In E. M. Hetherington (Ed.) and P. H. Mussen (Series Ed.), *Handbook of Child Psychology, (vol. 4), Socialization, personality and social development* (pp. 1-101). New York: Wiley.

MacVicar, S., Kirkpatrick, P., Humphrey, T., & Forbes-McKay, K. E. (2015). Supporting breastfeeding establishment among socially disadvantaged women: A meta-synthesis. *Birth: Issues in Perinatal Care, 42*, 290-298. https://doi.org/10.1111/birt.12180

Maddux, J. E. (2002). Stopping the 'madness': Positive psychology and the deconstruction of the illness ideology and the DSM. In C. Snyder & S. J. Lopez (Eds.), *Handbook of positive psychology* (pp. 13-25). New York: Oxford University Press.

Maddux. J. E., Gosselin, J. T., & Winstead, B. A. (2005). Conceptions of psychopathology: A social constructionist perspective. In J. E. Maddux & B. A. Winstead (Eds.), *Psychopathology: Foundations for a contemporary understanding* (pp. 3-18). New York: Lawrence Erlbaum Associates.

Maddux, J. E., Snyder, C. R., & Lopez, S. J. (2004). Toward a positive clinical psychology: Deconstructing the illness ideology and constructing an ideology of human strengths and potential. In P. A. Linley & S. Joseph (Eds.), *Positive psychology in practice* (pp. 320-334). Hoboken, NJ: John Wiley & Sons Inc.

Masten, A. S. (2007). Resilience in developing systems: Progress and promise as the fourth wave rises. *Development and Psychopathology, 19*, 921-930. doi: 10.1017/S0954579407000442

Masten, A. S. (2001). *Ordinary magic: Resilience processes in development.* Minneapolis, MN: University of Minnesota, Twin Cities Campus.

Masten, A. S. (2014). *Ordinary magic: Resilience in development.* New York, NY: The Guilford Press.

Masten, A. S., & Garmezy, N. (1985). Risk, vulnerability, and protective factors in developmental psychopathology. *Advances in Clinical Psychology, 8*, 1-52. doi: 10.1007/978-1-4613-9820-2_1

Masten, A. S., & Obradović, J. (2006). Competence and resilience in development. *Annals of the New York Academy of Sciences, 1094*, 13-27. doi: 10.1196/annals.1376.003

Masten, A. S., Garmezy, N., Tellegen, A., Pellegrini, D. S., Larkin, K., & Larsen, A. (1988). Competence and stress in school children: The moderating effects of individual and family qualities. *Journal of Child Psychology and Psychiatry, 29*, 745-764. doi: 10.1111/j.1469-7610.1988.tb00751.x

Matson, J. L., & LoVullo, S. V. (2009). Trends and topics in autism spectrum disorders research. *Research in Autism Spectrum Disorders, 3*, 252-257. doi: 10.1016/j.rasd.2008.06.005

Mazzucchelli, T., & Sanders, M (2012). *Stepping stones triple P: A population approach to the promotion of competent parenting of children with disability*. Queensland, Australia: University of Queensland.

McCrimmon, A. W., Matchullis, R. L., & Altomare, A. A. (2016). Resilience and emotional intelligence in children with high-functioning autism spectrum disorder. *Developmental Neurorehabilitation, 19*, 154-161. doi: 10.3109/17518423.2014.927017

McCrimmon, A. W., Climie, E. A., & Huynh, S. (2018). The relation between emotional intelligence and resilience in at-risk populations. *Developmental Neurorehabilitation, 21*, 326-335. doi: 10.1080/17518423.2017.1387873

McCrimmon, A. W., & Montgomery, J. M. (2014). Resilience-based perspectives for autism spectrum disorder. In S. Prince-Embury & D. Saklofske (eds.), *Resilience Interventions for Youth in Diverse Populations. The Springer Series on Human Exceptionality.* New York, NY: Springer. https://doi-org.login.ezproxy.library.ualberta.ca/10.1007/978-1-4939-0542-3_17

Miller, S. M., & Chan, F. (2008). Predictors of life satisfaction in individuals with intellectual disabilities. *Journal of Intellectual Disability Research, 52*, 1039-1047. doi: 10.1111/j.1365-2788.2008.01106.x

Montgomery, J. M., Stoesz, B. M., & McCrimmon, A. W. (2013). Emotional intelligence, theory of mind, and executive functions as predictors of social outcomes in young adults with Asperger syndrome. *Focus on Autism and Other Developmental Disabilities, 28*, 4-13. doi: 10.1177/10883576124615

Morrison, J. Q., Sansosti, F. J., & Hadley, W. M. (2009). Parent perceptions of the anticipated needs and expectations for support for their college-bound students with Asperger's' syndrome. *Journal of Postsecondary Education and Disability, 22*, 78-87.

Myers, D. G., & Diener, E. (1995). Who is happy? *Psychological Science, 6*, 10-19.

Nixon, C. L., & Cummings, E. M. (1999). Sibling disability and children's reactivity to conflicts involving family members. *Journal of Family Psychology, 13*, 274-285.

Norton, P. & Drew, C. (1994). Autism and potential family stressors. *The American Journal of Family Therapy, 22*, 67-76. doi: 10.1080/01926189408251298

Nursey, A. D., Rhode, J. R., & Farmer, R. D. T. (1991). Ways of telling new parents about their child and his or her mental handicap: A comparison of doctor's and parents' views. *Journal of Mental Deficiency Research, 35*, 48-57. https://doi.org/10.1111/j.1365-2788.1991.tb01030.x

Ong, A. D., Bergeman, C. S., Bisconti, T. L., & Wallace, K. A. (2006). Psychological resilience, positive emotions, and successful adaptation to stress in later life. *Journal of Personality and Social Psychology, 91*, 730-749. doi: 10. 1037/0022-3514.91.4.730

Padilla-Walker, L. M., Harper, J. M., & Jensen, A. C. (2010). Self-Regulation as a mediator between sibling relationship quality and early adolescents' positive and negative outcomes. *Journal of Family Psychology, 24*, 419-428. doi: 10.1037/a0020387

Pakenham, K. I., Samios, C., & Sofronoff, K. (2005). Adjustment in mothers of children with Asperger syndrome: An application of the double ABCX model of family adjustment. *Autism, 9*, 181-212. doi: 10.1177/1362361305049033

Patterson, J. M. (2002). Integrating family resilience and family stress theory. *Journal of Marriage and Family, 64*, 349-360. doi: 10.1111/j.1741-3737.2002.00349.x

Pinkerton, J., & Dolan, P. (2007). Family support, social capital, resilience and adolescent coping. *Child and Family Social Work, 12*, 219-228. https://doi-org.login.ezproxy.library.ualberta.ca/10.1111/j.1365-2206.2007.00497.x

Pottie, C. G., & Ingram, K. M. (2008). Daily stress, coping, and well-being in parents of children with autism: A multilevel modeling approach. *Journal of Family Psychology, 22*, 855-864. doi: 10.1037/a0013604

Pulg, A., Koro-Ljungberg, M., & Echevarrla-Doan, S. (2008). Social constructionist family systems research: Conceptual considerations. *The Family Journal: Counseling and Therapy for Couples and Families, 16*, 139-146. doi: 10.1177/1066480707313785

Radke-Yarrow, M. (1999). *Children of depressed mothers: From early childhood to maturity.* Cambridge, UK: Cambridge University Press.

Rieffe, C., Terwogt, M. M., & Kotronopoulou, K. (2007). Awareness of single and multiple emotions in high-functioning children with autism. *Journal of Autism and Developmental Disorders, 37,* 455-465. doi: 10.1007/s10803-006-0171-5

Rivers, J. W., & Stoneman, Z. (2003). Sibling relationships when a child has autism: Marital stress and support coping. *Journal of Autism and Developmental Disorders, 33*, 383-394. doi: 10.1023/A:1025006727395

Rodrigue, J. R., Morgan, S. B., & Geffken, G. R. (1990). Families of autistic children: Psychological functioning of mothers. *Journal of Clinical Child Psychology, 19*, 371-379. doi: 10.1207/s15374424jccp1904_9

Rutter, M. (1979). Maternal deprivation, 1972-1978: New findings, new concepts, new approaches. *Child Development, 50*, 283-305.

Rutter, M. (1987). Psychosocial resilience and protective mechanisms. *American Journal of Orthopsychiatry, 57*, 316-331. doi: 10.111/j.1939-0025.1987.tb03541.x

Rutter, M. L. (2011). Progress in understanding autism: 2007-2010. *Journal of Autism and Developmental Disorders, 41*, 395-404. doi: 10.1007/s10803-011-1184-2

Rutter, M. L. (2012). Resilience as a dynamic concept. *Development and Psychopathology, 24*, 335-344. doi: 10.1017/ S0954579412000028

Samson, A. C., & Antonelli, Y. (2013). Humor as character strength and its relation to life satisfaction and happiness in Autism Spectrum Disorders. *International Journal of Humor Research, 26,* 477-491. https://doi.org/10.1515/humor-2013-0031

Sanua, V. D. (1986). A comparative study of opinions of U.S.A. and European professionals on the etiology of infantile autism. *The International Journal of Social Psychiatry, 32*, 16-30.

Seligman, M. E. P., & Csikszentmihalyi, M. (2000). Positive psychology: An introduction. *The American Psychologist, 55*, 5-14. doi: 10.1037/003-066X.55.1.5

Seligman, M. E. P., Rashid, T., & Parks, A. C. (2006). Positive psychotherapy. *American Psychologist, 61*(8), 774-788.

Shalom, D. B., Mostofsky, S. H., Hazlett, R. L., Goldberg, M. C., Landa, R. J., Faran, Y., McLeod, D. R., & Hoehn-Saric, R. (2006). Normal physiological emotions but differences in expression of conscious feelings in children with high-functioning autism. *Journal of Autism and Developmental Disorders, 36*, 395-400. doi: 10.1007/s10803-006-0077-2

Siman-Tov, A. & Kaniel, S. (2011). Stress and personal resource as predictors of the adjustment of parents to autistic children: A multivariate model. *Journal of Autism and Developmental Disorders, 41*, 879-890. doi: 10.1007/s10803-010-112-x

Smith, M. (2011). Measures for assessing parenting in research and practice. *Child and Adolescent Mental Health, 16*, 158-166. doi:10.1111/j.1475-3588.2013.00585.x

Smith, L. E., Hong, J., Seltzer, M. M., Greenberg, J. S., Almeida, D. M., & Bishop, S. L. (2010). Daily experiences among mothers of adolescents and adults with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*, 167-178. doi: 10.1007/s10803-009-0844-y

Sroufe, L. A., Carlson, E. A., Levy, A. K., & Egeland, B. (1999). Implication of attachment theory for developmental psychopathology. *Development and Psychopathology, 11*, 1-13.

Steiner, A. M., & Gengoux, G. W. (2018). Strength-based approaches to working with children with ASD. In M. Siller, & L. Morgan (Eds.), *Handbook of Parent-Implemented Interventions for Very Young Children with Autism: Autism and Child Psychopathology Series* (pp. 155-168). Springer, Cham. https://doi.org/10.1007/978-3-319-90994-3_10

Stokar, Y. N., Baum, N. L., Plischke, A., & Ziv, Y. (2014). The key to resilience: A peer based youth leader training and support program. *Journal of Child and Adolescent Trauma, 7*, 111-120. doi: 10.1007/s40653-014-0016-x

Taylor, J. L., & Warren, Z. E. (2012). Maternal depressive symptoms following autism spectrum diagnosis. *Journal of Autism and Developmental Disorders, 42,* 1411-1418. doi: 10.1007/s10803-011-1375-x

Terry, D. & Hynes, G. (1998). Adjustment to a low-control situation: Reexamining the role of coping responses. *Journal of Personality and Social Psychology, 74*, 1078-1092. doi: 10.1037/0022-3514.74.4.1078

Tharinger, D. J., Finn, S. E., Gentry, L., Hamilton, A., Fowler, J., Matson, M., … Walkowiak, J. (2009). Therapeutic assessment with children: A pilot study of treatment acceptability and outcome. *Journal of Personality Assessment, 91*, 238-244. doi: 10.1080/00223890902794275

Timmons, L., & Ekas, N. V. (2018). Giving thanks: Findings from gratitude intervention with mothers of children with autism spectrum disorder. *Research in Autism Spectrum Disorders, 49,* 13-24. https://doi.org/10.1016/j.rasd.2018.01.008

Tobing, L. E. & Glenwick, D. S. (2007). Predictors and moderators of psychological distress in mothers of children with pervasive development disorders. *Journal of Family Social Work, 10*, 1-22. doi: 10.1300/J039v10n04_01

Truitt, M., Biesecker, B., Capone, G., Bailey, T., & Erby, L. (2012). The role of hope in adaptation to uncertainty: The experience of caregivers of children with Down syndrome. *Patient Education and Counseling, 87*, 233-238. doi: 10.1016/j.pec.2011.08.015

Uljarević, M., & Evans, D. W. (2017). Relationship between repetitive behaviour and fear across normative development, autism spectrum disorder, and down syndrome. *Autism Research, 10*, 502-507. https://doi-org.login.ezproxy.library.ualberta.ca/10.1002/aur.1674

Uljarević, M., & Hamilton, A. (2013). Recognition of emotions in autism: A formal meta-analysis. *Journal of Autism and Developmental Disorders, 43*, 1517-1526. doi: 10.1007/s10803-012-1695-5

Van Breda, A. D. (2001). *Resilience theory: A literature review.* Pretoria, South Africa: South African Military Health Service.

Volkmar, F. R., & Pauls, D. (2003). Autism. *The Lancet, 362*, 1133-1141. http://dx.doi.org/10.1016/S0140-6736(03)14471-6

Walsh, F. (2003). Family resilience: A framework for clinical practice. *Family Process, 42*, 1-18. doi: 10.1111/j.1545-5300.2003.00001.x

Walsh, F. (2010). A family resilience framework for clinical practice: Integrating developmental theory and systemic perspectives. In W. Borden (Ed.), *Reshaping theory in contemporary social work: Toward a critical pluralism in clinical practice* (pp. 146-176). New York, NY: Columbia University Press.

Wayment, H. A., Al-Kire, R., & Brookshire, K. (2018). Challenged and changed: Quiet ego and posttraumatic growth in mothers raising children with autism spectrum disorder. *Autism, 0*, 1-12. doi: 10/1177.1362361318763971

Williams, R., Alexander, D. A., Bolsover, D., & Bakke, F. K. (2008). Children, resilience and disasters: Recent evidence that should influence a model of psychosocial care. *Current Opinion in Psychiatry, 21*, 338-344. doi: 10.1097/YCO.0b013e328305b6e4

Williams, D., & Happé, F. (2010). Recognising ‘social’ and ‘non-social’ emotions in self and others: A study of autism. *Autism, 14*, 285-304. https://doi-org.login.ezproxy.library.ualberta.ca/10.1177/1362361309344849

Wood, A. M., & Tarrier, N. (2010). Positive clinical psychology: A new vision and strategy for integrated research and practice. *Clinical Psychology Review, 30*, 819-829. doi: 10.1016/j.cpr.2010.06.003

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: the experience of parents who have a child with autism. *Qualitative Health Research, 18*, 1075-1083. doi: 10.1177/1049732308320112

Zand, D. H., Braddock, B., Baig, W., Deasy, J., & Maxim, R. (2013). Role of pediatricians in fostering resilience in parents of children with autism spectrum disorder. *The Journal of Pediatrics, 163,* 1769-1771. doi: doi:10.1016/j.jpeds.2013.06.074

Appendix A: Informed Consent

Title of Study: Promoting familial resilience through ASD diagnostic assessment: An enhanced critical incident technique study

Student Research: Kristy L Dykshoorn (dykshoor@ualberta.ca)

Principle Investigator: Dr. Damien Cormier (dcormier@ualberta.ca)

Why am I being asked to take part in this research study? You are being asked to be in this study because you are a parent or caregiver of a child who has been diagnosed with Autism Spectrum Disorder (ASD) within the last year in Alberta, Canada. This research is being done to gain a better understanding of the effect the ASD diagnosis appointment has on the family's well-being; specifically, the family's resilience. This information will be used to inform those conducting ASD diagnosis assessments of important techniques and factors that help to enhance family resilience. These techniques can then be used in the ASD diagnostic assessment process to help prepare parents/caregivers for the new journey of raising a child with ASD

If you have any questions about the information in this form, please contact Kristy at dykshoor@ualberta.ca before you make a decision to participate or not. You are encouraged to ask questions if you feel anything needs to be made clearer. You will be offered a copy of this form for your records.

What is the reason for doing the study?
Family Resilience is the ability of one's family to successfully manage trying or difficult life circumstances and to maintain healthy functioning during a significant stressor. For many, the diagnosis of a child with Autism Spectrum Disorder (ASD) can be very stressful and can threaten a family's resilience. One of the first points of contact after a child has been diagnosed with ASD, is the physician or psychologist who conducted the ASD diagnostic assessment, therefore, it is important that these professionals recognize the effect they have on the family's ability to cope with the changes ASD brings to a family.

By asking you (as a participant) to describe your experience during the ASD diagnostic assessment appointment, we will be gathering valuable information that can be used to educate those conducting ASD diagnosis appointments. This information will be used to provide information about what you, the parents/caregivers, found helpful and what you found unhelpful in preparing you to raise a child with ASD. Future caregivers will benefit from the information you provide, because their diagnosis assessment appointments will be more focused on building family resilience.

What will I be asked to do? Participation in this study will require approximately one or two hours of your time, split between an interview and a follow up credibility check. During an hour long in-person (or via telephone or Skype, as needed), we will discuss your diagnosis experience. Finally, you will be asked to review the interview information once it has been summarized and separated into categories.

Semi-Structured Interview
This interview will be approximately 1-hour long, and you will be asked about your specific experiences during the ASD diagnosis assessment process. More specifically, you will be asked what specific incidences during the assessment helped and hindered your experience of resilience. At the end of this interview, you will be asked if I can contact you in the coming months to verify the specific themes and categories that emerged from our interview.

Data Verification
If you have given permission, you will be contacted (via email or phone) to review the themes and categories that were developed during the data analysis phase of the study. The purpose of this phase is to ensure that the results remain true to the participant's intentions and meaning. It is during this phase that you would be encouraged to make clarifications and corrections to any of the themes and categories that did not fit your experience.

What are the risks and discomforts? It is anticipated there will be no risks associated with this research study. However, at times, some people can feel a bit uncomfortable with questions about family life or distressed if questions remind them of negative life experiences. If this happens and the distress becomes problematic, I can provide referrals and/or information regarding counselling practices in the community that may be of help.

It is not possible to know all of the risks that may happen in a study, but the researchers have taken all reasonable safeguards to minimize any known risks to a study participant.

What are the benefits to me? Many people experience satisfaction from contributing to research that can be helpful to families and especially families in similar circumstances. Some people find it interesting and helpful to think about their family when answering these kinds of questions. However, you may not get any benefit from being in this research study.

This study may help other families with a child being assessed for ASD in the future.

Do I have to take part in the study? Being in this study is your choice. If you decide to be in the study, you can change your mind and stop being in the study at any time, and it will in no way affect the care that you are entitled to. You do not have to answer any questions that you do not feel comfortable answering. You are able to withdraw from the interview at any time and your data will be deleted. If you complete the interview and later decide that you do not wish to be part of the study, your data will be deleted.

Will I be paid to be in the research? If you choose to complete participation in the study, you will be given a $20.00 gift card of your choice (Tim Horton's, Chapters, or Wal-Mart). Even if you decide to withdraw early, you will still be entitled to the gift card or a portion thereof.

Will my information be kept private? During the study, we will be collecting data about you. We will do everything we can to make sure that this data is kept private. No data relating to this study that includes your name will be released outside of the researcher's office or published by the researchers. Sometimes, by law, we may have to release your information with your name, so we cannot guarantee absolute privacy. However, we will make every legal effort to make sure that your information is kept private

The interviews will be audio recorded for data collection purposes. After the interview, however, the audio recordings will be converted into written transcripts, verified, and then the audio recording securely stored for 5 years, as is required. The transcripts will have all identifying information removed, will be encrypted, and password protected on my personal computer.

What if I have questions?
If you have any questions about the research now or later, please contact Kristy Dykshoorn at dykshoor@ualberta.ca.

If you have any questions regarding your rights as a research participant, you may contact the Health Research Ethics Board at 780-492-2615. This office has no affiliation with the study investigators.

CONSENT

Title of Study: Promoting familial resilience through ASD diagnostic assessment: A mixed methods study

Student Researcher: Kristy L Dykshoorn **Email:** dykshoor@ualberta.ca
Principle Investigator: Dr. Damien Cormier **Email:** dcormier@ualberta.ca

	Yes	No
Do you understand that you have been asked to be in a research study?	☐	☐
Have you read and received a copy of the attached Information Sheet?	☐	☐
Do you understand the benefits and risks involved in taking part in this research study?	☐	☐
Have you had an opportunity to ask questions and discuss this study?	☐	☐
Do you understand that you are free to leave the study at any time without having to give a reason and without affecting your care?	☐	☐
Has the issue of confidentiality been explained to you?	☐	☐
Do you understand who will have access to the information you provide?		

Who explained this study to you?
____

I agree to take part in this study:
Signature of Research Participant ______________________________________

(Printed Name) ______________________________________

Date: ________________________

I believe that the person signing this form understands what is involved in the study and voluntarily agrees to participate.

Signature of Investigator or Designee_________________________________ Date __________

THE INFORMATION SHEET MUST BE ATTACHED TO THIS CONSENT FORM AND A COPY GIVEN TO THE RESEARCH PARTICIPANT

Appendix B: ECIT Interview Protocol

Semi-structured Interview Protocol:

Participant #: ___________________ Date: ______________________
Interview Start Time: _____________

1) *Contextual Component*

   Preamble: As you know, I am investigating the ways in which the ASD diagnostic assessment affects family resilience. The purpose of this interview is to collect information about the experiences you had during the ASD diagnostic assessment process that were significant to you.

   a. As a way of getting started, perhaps you could tell me a little bit about the assessment process.
   b. You have volunteered to participate in this study because you identified yourself as experiencing family resilience to some degree. What does "family resilience" mean to you?
   c. In your opinion, did your experience during the ASD diagnostic assessment have an effect on your family's resilience?
   d. If so, how have these changes affected your family life? (Probe, as needed: Are there any other impacts on your family?)

2) *Critical Incident Component*

   Transition to Critical Incident questions: You said that some of your experience during the ASD diagnostic assessment may have impacted your family's resilience.

   a. What, during the ASD diagnostic assessment, helped you and your family feel more resilient? (Probes: what was the incident/factor? How did it impact you? Can you give me a specific example?)

Helpful Factor & What it Means to Participant (What do you mean by …?)	Importance (How did it help? Tell me what it was about … that you find so helpful.)	Example (What led up to it? Incident. Outcome of incident.)

   b. Are there things that have made it more difficult for your family to feel resilient? (Alternative question: What kinds of things happened during the ASD diagnostic assessment that made it harder for you and your family to feel resilient?)

Hindering Factor & What it Means to Participant (What do you mean by…?)	Important (How did it hinder? Tell me what it was about … that you find so unhelpful.)	Example (What led up to it? Incident. Outcome of incident.)

c. Summarize what has been discussed up to this point with the participant as a transition to the next question:
We've talked about what's helped you and your family feel resilience (name them), and some things that have made it more difficult for you and your family to feel resilient (name them). Are there other things that would help you and your family to feel resilient? (Alternative question: I wonder what else might have been helpful for you that you didn't experience during the ASD diagnostic assessment?)

Wish List Item & What it Means to Participant (What do you mean by …?)	Importance (How would it help? Tell me what it is about … that you would find so helpful.)	Example (In what circumstances might this be helpful?)

d. Did you and your family expect the diagnosis of ASD?
(Circle one) Yes No
e. If not, what was your reaction?

3) *Demographics Component*
   a. Gender:
   b. Age:
   c. Highest level of education:
   d. Yearly total household income:
   e. Relationship status:
   f. Religious/cultural affiliations:
   g. Heritage/cultural background:
   h. Country born in:
      i. If not Canada, age moved to Canada:
   i. Country mother/father was born in:
   j. Gender of child diagnosed with ASD:
   k. Age of child diagnosed with ASD:

l. Relevant family background information:

4) *Conclusion*
Is there anything else you'd wish to tell me about your experience during the ASD diagnostic assessment process?

Interview End Time: ___________________ Length of Interview: _________________
Interviewer's Name: ____________________