

UNIVERSITY OF CALGARY

Families Journeying Together:

Exploring Resilience in Families with Adolescents with ADHD

by

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## Abstract

There is increasing attention given to the ways that children and adolescents with ADHD experience resilience and factors that help them to thrive. Research in this area is particularly needed for the relatively understudied group, emerging adolescents, who are experiencing a key transitional stage of life and are at risk for developing significant comorbidities. The purpose of this study was to explore the experience of resilience among emerging adolescents and their families. Using a qualitative, constructivist grounded theory approach, 21 interviews were conducted with parents and primary caregivers of emerging adolescents with ADHD, adolescents with ADHD and supportive professionals who work directly with this population. Participants were from three Canadian cities. A resilience-promoting process emerged of *Families Journeying Together*. It comprised three parts of *experiencing constant challenge, building family consciousness, and moving forward*. The findings underlined the key role that parents play in the lives of emerging adolescents with ADHD, and the need to include a family systems perspective when exploring resilience in ADHD. Participants affirmed the relevance of an ecological approach to understanding and supporting resilience for emerging adolescents with ADHD and their families. Findings suggest future research and policy/program development that focuses upon ecological factors to nurture resilience and well-being.

## Table of Contents

Abstract .....	ii
List of Tables .....	vi
List of Figures and Illustrations .....	vii
Chapter 1: Introduction .....	8
1.1 The Need to Explore Positive Outcomes of ADHD .....	8
1.2 A Social Work Perspective .....	9
1.3 Purpose and Significance of the Study .....	9
1.4 Positionality .....	10
Chapter 2: Theoretical Influences .....	11
2.1 Resilience Theory .....	11
2.1.1 The Concept of Resilience .....	11
2.1.2 Models of Resilience .....	12
2.1.3 Ecological Frameworks of Resilience .....	13
2.1.4 Building Resilience .....	15
2.1.5 Limitations and Criticisms of the Resilience Model .....	17
2.1.6 Resilience Theory Summary .....	18
2.2 Disability Theory .....	19
2.2.1 The Social Model of Disability .....	19
2.2.2 The Social Relational Model of Disability .....	20
2.2.3 The Social Relational Model and Childhood Disability .....	22
2.2.4 ADHD and the Social Relational Model of Disability .....	23
2.2.5 Disability Theory Summary .....	24
2.3 Anti oppressive Social World .....	24
Chapter 3: Literature Review .....	26
3.1 Understanding ADHD .....	26
3.1.1 ADHD: Diagnostic Criteria and Characteristics .....	26
3.1.2 Classification of ADHD .....	27
3.1.3 Causes of ADHD .....	28
3.1.4 Comorbidities and Risks of Adverse Outcomes .....	29
3.1.5 Social Relations .....	31
3.1.6 Societal Impacts of ADHD .....	32

3.1.7	Family Relationships and ADHD .....	33
3.1.8	Treatment Approaches .....	35
3.1.9	Differential Outcomes in Children and Adolescents with ADHD.....	36
3.1.10	Summary of Relevant ADHD Research .....	39
3.2	Emerging Adolescence.....	40
3.2.1	Theories of Adolescence and Early Adolescence .....	40
3.2.2	Parent-Child Relationships in Emerging Adolescence .....	41
3.2.3	Attachment and Emerging Adolescence.....	42
3.2.4	Summary of Emerging Adolescence Literature.....	43
3.3	The Need for this Study .....	44
3.4	The Goal of this Study and Research Questions .....	45
Chapter 4: Methodology .....		47
4.1	Theoretical Foundations.....	47
4.2	Considerations Underlying Design Choice .....	47
4.3	Constructivist Grounded Theory .....	48
4.4	Research Design.....	50
4.4.1	Initiative for the Research.....	50
4.4.2	Sampling .....	51
4.4.3	Setting and Recruitment.....	52
4.4.4	Interview Methods .....	54
4.5	Data Analysis .....	55
4.5.1	Overview of Analytical Process.....	55
4.5.2	Constant Comparative Method .....	55
4.5.3	Data Sufficiency.....	57
4.5.4	Application of Data Analysis Process.....	57
4.6	Ethics.....	58
4.7	Rigour.....	60
Chapter 5: Study Findings .....		61
5.1	Overview .....	61
5.2	Demographics.....	63
5.3	Understandings of Resilience.....	64
5.4	A Core Category: Families Journeying Together .....	67

5.4.1	Experiencing Constant Challenge.....	70
5.4.2	Building Family Consciousness.....	78
5.4.3	Moving Forward. ....	85
5.4.4	Summary of Findings.....	98
Chapter 6: Discussion, Limitations and Recommendations .....		99
6.1	Resilience of Early Adolescents with ADHD .....	100
6.2	Family Resilience.....	102
6.3	Ecological Resilience .....	106
6.4	Limitations .....	108
6.5	Recommendations .....	110
Chapter 7: Conclusion.....		113
References.....		115
APPENDIX A: CONSENT FORMS FOR PARENT/CAREGIVER PARTICIPANTS AND PROFESSIONAL PARTICIPANTS .....		144
APPENDIX B: ASSENT FORM FOR ADOLESCENTS .....		150
APPENDIX C: INTERVIEW GUIDES .....		152
APPENDIX D: PARTIAL MEMO .....		154

## List of Tables

Table 1. Selected Symptoms of ADHD .....	26
Table 2. Demographic Information of Participants.....	64

## **List of Figures and Illustrations**

Figure 1. Families Journeying Together .....	70
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## **Chapter 1: Introduction**

### **1.1 The Need to Explore Positive Outcomes of ADHD**

ADHD (Attention-Deficit Hyperactivity Disorder) is a neurodevelopmental condition that affects the social, emotional, cognitive and behavioral development of children and adolescents, placing them at significant risk for numerous adverse outcomes. The families of those with ADHD are also at increased risk of adverse outcomes, including mental health problems and marital and familial breakdown (Barkley, 2013). The significant body of research on ADHD has focused upon the biological aspects of the condition, and the risk of adverse outcomes for those with the condition and their families. Less research has focused upon positive outcomes and the range of factors that have contributed to these outcomes. There is a particular need for research on the experience of early or emerging adolescents in the developmental period from approximately 10-15 years when a child begins puberty (Hill, 1980) and when adolescents with ADHD are at increased risk of developing serious behavioral conditions such as conduct disorder.

The theory of resilience offers a helpful framework to explore factors that may contribute to or impede positive outcomes for emerging adolescents with ADHD. Models of resilience such as that of Ungar (2004, 2008, 2012, 2015a, 2015b) and Masten (2001, 2010, 2014) allow for exploration through an ecological lens, identifying the individual, family, community and societal factors that may interact to influence resilience. These include the role of the family system in nurturing its own resilience and in turn that of an adolescent member, and the way that the broader environment influences resilience.

## **1.2 A Social Work Perspective**

Although ADHD has been widely studied, there is limited research on the daily experience of those living with the condition, and particularly little from a strengths-based perspective. Research of this nature is important to the practice of social work given that it upholds social workers' ethical responsibility to build knowledge that will support both the development of individuals and a just, diverse and inclusive society (Canadian Association of Social Workers, 2005a). Such study can further assist in building knowledge that supports individual empowerment and “bring(s) about greater understanding and insight for policy makers and the public” (Canadian Association of Social Workers, 2005b, p. 24). Research of this nature, which seeks the voice of those most directly affected by ADHD holds the promise of informing, and potentially improving, the quality of care they receive (Baldwin et al., 2015; Richie, 2015, p. 67). Arguably, pursuant to Article 12 of the international agreement the *Convention on the Rights of the Child*, it may also enhance measures that support the rights and dignity of the adolescent with ADHD and family members, including siblings, who may be affected by a brother or sister's condition (The United Nations, 1989).

## **1.3 Purpose and Significance of the Study**

Given the above, in this study, I seek to contribute to the emerging body of research by eliciting elements that promote resilience in children and adolescents with ADHD. I do this from within the field of social work, including an ecological framework and the perspective of anti-oppressive research and practice. Specifically, in this study, I explore: (a) the nature and experience of resilience for emerging adolescents with ADHD and their families; and (b) personal, family, community and environmental factors that contribute to this resilience.

Exploration is done through the eyes and voices of those most directly connected to the experience of resilience, including adolescents with ADHD, parents/caregivers of the adolescents and professionals who support these adolescents and their families.

#### **1.4 Positionality**

Positionality represents the “relational place or value one has that influences and is influenced by varying contexts” (Louis & Barton, 2002, p. 3). It underlines the role of power and privilege in the research encounter, including the “insider-outsider” relationship of a researcher to the community under study (Collins, 1999). The positionality of a researcher influences all stages of the research, including the interpersonal encounter of a qualitative interview and the conclusions that are drawn from the research (Fine, 1994). While positionality should not become self-indulgent narcissism, appropriate disclosure of a researcher’s characteristics, including personal and structural characteristics, allows the reader to make informed judgements regarding research conclusions (Sharpe, 2017).

I am a middle aged, middle class female. As a member of and advocate within Ontario’s ADHD community, I have a strong interest in lifting the voice of those affected by ADHD and other invisible disabilities to ensure that they receive adequate and appropriate support to meet their potential. As a former criminal lawyer, I have an interest in the ways that adolescents with ADHD may “slip through the cracks” of educational and community systems, experience adverse outcomes, and become involved in the justice and correctional system. I hope that this study may contribute to knowledge gain, service improvements and ameliorated experience for those with ADHD and their families.

## **Chapter 2: Theoretical Influences**

There are three key areas of theory that have influenced this research: resilience theory, disability theory and the anti-oppressive framework. Each of these theoretical influences are briefly summarized below.

### **2.1 Resilience Theory**

#### **2.1.1 The Concept of Resilience**

Resilience is commonly associated with strengths-based approaches. These developed as a critique of problem-focused medical models that emphasize the identification of challenge and ways it may be removed or reduced (Zimmerman, 2013). Strengths-based approaches seek to identify and enhance factors that promote resilience rather than focusing upon “reducing exposure to risk or ameliorating (an individual’s) deficits” (Zimmerman, 2013, p. 215). A key focus of strengths-based approaches is the assets that a client brings to working relationships with supportive professionals and their co-production rather than the simple receipt of service (Morgan & Ziglio, 2007). As such these approaches represent an alternative viewpoint to models which focus on pathological responses to stress and adversity.

Within strengths-based approaches, a focus has come to rest upon the concept of resilience developed in professions such as engineering, and the ways that it can explain how some individuals experience positive outcomes amidst stress and adversity, while others do not (Fleming & Ledogar, 2008). For *at risk* adolescents, for example, there is focus on how some adolescents experience positive outcomes in the face of disability, trauma, loss and adverse experience such as poverty and homelessness (Fleming & Ledogar, 2008). Resilience is

generally understood to disrupt the causal relationship between the experience of stress and adverse life outcomes (Masten, 2001).

In the last 20 years, there have been three notable developments in the theory of resilience that have influenced this research. First, while it is most commonly understood as the process of positive adaptation within experiences of adversity (Luthar, Sawyer & Brown, 2006), resilience has also come to include aspects of positive post-traumatic development. Resilience, therefore, is increasingly thought of not only as involving a return to status quo after a challenge, but further, experiencing positive development that allows an individual to thrive through and after adversity. Second, from being originally conceived as a discrete asset, resilience is increasingly understood to exist on a continuum (Hunter & Chandler, 1999), with the possibility that individuals may experience resilience in one domain, for example at school, but not in others, for example, unstructured social situations (Fleming & Ledogar, 2008). Finally, as is further discussed below, an initial focus upon individual traits has been expanded to a broader conceptualization of resilience. Of particular note, there is an increasing recognition that resilience can be understood within an ecological framework that acknowledges the ways that environmental factors may support an individual in addressing adversity, or even, in avoiding it in the first place.

### **2.1.2 Models of Resilience**

One's level of resilience is commonly understood to be influenced by the relative balance of risk and protective factors that are experienced. Risk factors are "probability markers, social address indicators, correlates and causes that increase the likelihood of the onset or maintenance of a problem of pathology" (Kia-Keating, Dowdy, Morgan, & Noam, 2011, p. 221). In contrast,

protective factors modify or reduce the effect of risk factors, helping to support and promote healthy development (Zimmerman, 2013).

There are three commonly accepted models for how risk and protective factors interact (Fleming & Ledogar, 2008; Herrick et al., 2014). According to the *compensatory* model, protective factors neutralize risk factors. According to the *protective* model, protective factors reduce, or moderate risk factors. In contrast to the two preceding models, according to the *challenge* model, exposure to a moderate level of risk may be considered positive and is believed to act as “inoculation” to prepare an individual to overcome adversity and develop coping strategies (Zimmerman, 2013, p. 216).

This review and analysis primarily rely upon a protective model, understanding protective factors to operate as “moderators, acting as a buffer to disorder or dysfunction, or affect(ing) the mediation chain between adversity and negative outcomes” (Kia-Keating, Dowdy, Morgan, & Noam, 2011, p. 221). This is arguably the dominant understanding of resilience in Canadian psychological and social work practice given its apparent role in documents such as Barankin and Khanlou’s important book *Growing up Resilient* (2007), published by the Canadian Association of Mental Health, which considers that adolescent experience reflects a greater probability of resilience when protective factors are maximized, and risk factors are minimized.

### **2.1.3 Ecological Frameworks of Resilience**

Dominant theories of resilience focus upon individual-level factors, including beliefs about the self and personality traits in accounting for experiences in, and responses to, adversity. Within these frameworks, family factors such as parent-child relationships and parental role

modelling have also been identified as playing a significant role in healthy child and adolescent development (Caldwell et al., 2004).

A central critique is that these approaches may place too strong an emphasis upon the individual, failing to account for social and structural factors; relatedly, they may amplify dominant over minority social and ethnic experience (Colpitts & Gahagan, 2016). A strong voice of this critique from within the field of social work is Michael Ungar (2004), who underlines the importance of situating individual factors within their broader social, cultural, political, and economic context. Drawing upon the work of Bronfenbrenner (1976; 1992), Ungar developed a social-ecological model of resilience which situates the individual as existing within concentric circles of experience: from the *microsystem*, where an individual spends most of their time and which includes the family, to the *exosystem*, which exists outside the daily, direct experience of the individual.

Ungar emphasized the role of social ecologies, arguing that environmental factors have an equal to or greater effect on developmental outcomes than individual factors (Ungar, 2015a). For Ungar (2015b), “the locus of control for change in life trajectories” (p. 51) is, thus

external to the child, though a positive disposition and willingness to take advantage of these resources can help individuals develop in positive ways. For this reason, resilience is increasingly being thought of as the capacity of systems to adapt, rather than the capacity of individuals to overcome challenges. (Ungar, 2015b, p. 51)

Ungar (2008) further stated that the key role of the individual is navigating through their environment for resources:

Resilience is both the capacity of individuals to navigate their way into psychological, social, cultural, and physical resources that sustain their well-being and their individual and collective capacity to negotiate for these resources to be provided and experienced in culturally meaningful ways. (p. 225)

The relationship between the individual and their environment is best understood not as one of linear effect in either direction but as “chaotic, complex, relative, and contextual” (Ungar, 2004, p. 342). Building upon this work, Roberto and Moleiro (2016) considered resilience as dynamic, constructed and with a “plurality of meanings” (p. 931) depending upon resources available to individuals at a given time within a given context. Notably, for Ungar and others, a focus on systemic, ecological factors not only reflects empirical data but also places the burden appropriately on society for ensuring an adequate quality of life for all children and adolescents (Ungar, 2008).

Like others, Masten and Cicchetti (2010), Masten and Monn (2015) and Masten (2017) built upon this view of micro systemic factors in their work on children facing various forms of adversity, including armed conflict. Masten and Cicchetti (2010) addressed how multiple, interacting systems cumulatively impact upon the development of individuals. They also explore how individuals, acting collectively and over time, may influence the evolution of systems. The relationship of collectivity between individuals underlines the need for a dynamic, robust understanding of individual and family resilience, and particularly the ways that an individual child or adolescent is influenced by resilience-related factors in their micro system, including the family (Masten 2017; Masten & Monn, 2015).

#### **2.1.4 Building Resilience**

The question of how resilience arises and whether it is innate or built relates to debates about individual and ecological influences on resilience. Although most literature rejects the “myth” that resilience is reducible to innate personality traits (Witt, 2003, p. 177), there is often a focus away from ecological factors and towards ways by which individuals can build their own resilience. For example, the American Psychological Association’s *Road to Resilience* (2017) notes research that suggests a “primary factor in resilience is having caring and supportive relationships within and outside the family” (para. 8). Nonetheless, the focus of its document is the individual and ten strategies they can use to promote their own resilience (paras. 13-23). These strategies include: “Make connections”, “Move toward your goals”, “Take decisive actions”, “Look for opportunities for self discovery” and “Maintain a hopeful outlook” (paras. 13,16, 17, 18 and 21).

For adolescent populations, Ungar and others emphasized that strategies and approaches supporting resilience need to match adolescents’ “multiple contexts” (Witt, 2003, p. 179). Thus, for example, a line of research has examined environmental factors that may help build resilience for at risk adolescents, such as appropriate sports and recreation (Hopper & Iwaski, 2017). Nonetheless, as with the general literature on resilience-building, a key focus remains on how adolescents can be taught to increase their personal resilience. For example, in recent research, Taylor (2018) explored how adolescents at risk of sexual exploitation can be taught to improve decision making, and McAllister, Knight, Hasking, Withyman, and Dawkins (2018) addressed how adolescents experiencing adverse mental health can improve their coping skills. Notably, even within literature on personal resilience-building and despite the accepted importance of supportive relationships, there is limited literature that has examined how resilience can be built within an adolescent’s family system.

### **2.1.5 Limitations and Criticisms of the Resilience Model**

A strong criticism of theories of resilience, including many ecological models, is that they tend to favor traditional norms of and foci on behavior and outcomes (Collins, 2017, p. 87). For example, Ungar (2008, 2012) argued that they fail to adequately account for how cultural factors affect means by which resilience is understood and approached. This criticism has been addressed by scholars such as Ungar (2004, 2008, 2015), Roberto and Moleiro (2016) and Masten (2014a, 2014b, 2017) who emphasized the plural nature of resilience and the negotiated, dynamic relationship between the individual and their environment.

However, a more salient critique is that by focusing upon adversity, resilience models “overemphasize negative outcomes and overlook positive ones” (Kia-Keating, Dowdy, Morgan, & Noam, 2011, p. 221). In addition, they have generally failed to include at all, or adequately, the concept from Positive Youth Development (Lerner, Dowling, & Anderson, 2003; Lerner, Almerigi, Theokas, & Lerner, 2005; Lerner et al., 2012) of thriving, namely the “dynamic and bi-directional interplay of a young person intrinsically animated and energized by discovering his/her specialness and the developmental contexts (people/places) that know, affirm, celebrate and guide its expression” (Benson & Scales, 2009, p. 90). According to concepts of thriving, in the face of adversity, adolescents may not only overcome challenges but experience positive growth because of them. This concept of thriving is part of the broader framework of Positive Youth Development which is strengths-based and highlights the role of social work in helping adolescents to form positive, hopeful identities and to ultimately make a positive contribution to their societies (Lerner, Dowling, & Anderson, 2003; Lerner, Almerigi, Theokas, & Lerner, 2005).

Responding to concern regarding an over-emphasis upon negative outcomes, Masten (2001) identified resilience “as a class of phenomena characterized by good outcomes despite serious threats to adaptation or development” (p. 228). Building upon this link between overcoming adversity and thriving, Kia-Keating, Dowdy, Morgan and Noam (2011) integrated concepts of resilience and Positive Youth Development within an overall ecological framework. Their model includes both risk and protective factors, and developmental assets, which they defined as “internal and external strengths within an individual's social ecology that are predictive of positive outcomes, including health, mental health, and education” (Kia-Keating, Dowdy, Morgan & Noam, 2011, p. 221). Resilience factors and developmental assets are integrated across broad domains of adolescent development, including social, emotional, behavioral, moral, cognitive and structural. This model may be helpful in broadening understandings of resilience for those facing persistent challenge due to immutable characteristics, as is the case with ADHD.

### **2.1.6 Resilience Theory Summary**

Resilience theory is a helpful framework to build understanding about how some adolescents facing adversity not only overcome challenge, but, further, experience positive life outcomes and thrive. However, a key criticism of resilience models is their overemphasis upon personal resilience factors and a corresponding focus in popular and academic literature on how individuals may build their own resilience. Approaches such as Ungar’s (2004, 2008, 2015a, 2015b) social ecological model underline the importance of ecological factors for resilience in adolescents who are at risk of adverse life outcomes. This includes the ways that poverty and marginalization may impede resilience, and how resilient individuals and families can navigate and negotiate to improve their resources. Masten’s Developmental Systems Theory (Masten &

Cicchetti, 2010; Masten & Monn, 2015; Masten, 2017) emphasizes a bi-directional relationship between an individual and their environment, including ways that individuals and families can, at times, influence their environment.

Masten (2001, 2014b) and Kia-Keating, Dowdy, Morgan, and Noam (2011) advocated a model of resilience that includes concepts from Positive Youth Development – suggesting that resilience need not only imply overcoming adversity to return to a status quo, but also moving beyond it to achieve positive outcomes that support thriving. Both the ecological focus and concept of thriving are important for adolescents with ADHD, who experience persistent, immutable challenges and whose lives are affected not only by personal factors, but also by the environmental supports they need to help them meet their potential across domains of their lives.

## **2.2 Disability Theory**

### **2.2.1 The Social Model of Disability**

In a 1996 article, Susan Wendell described a question that continues to animate debate regarding disability theory: “Who defines disability and for what purposes?” (1996, p. 23). A dominant school of thought, the biomedical model, has answered the question by focusing primarily upon the individual considered to be ‘disabled’ – basing the definition of disability upon their corporal condition and experience (Reindal, 2010). At its core, the individual is understood as variant from a “normal” standard (Thomas, 2007; Reindal, 2010), and the biomedical model aims are to develop treatments and supports to modify the way that the individual interacts with his or her environment (Johnston & Dixon, 2014).

The social model has generally developed in response to what is considered an over-reductionist focus in the biomedical model on “individual pathological dejectedness” (Slee &

Allan 2001, p. 179). It considers disability not the result of a physiological condition or impairment but rather the result of society's response to it (Finkelstein & French, 1993; Oliver 1990, 1996, 2013). As such, it constitutes an alternative discourse based upon the central premise that "(people with disabilities) were not disabled by... impairments but by the disabling barriers (they) faced in society" (Oliver, 2013, p. 1024). Within the social model, the social environment is the focus for change rather than the individual considered to be disabled.

An implication of the social model is a reconsideration of what is considered "normal" within society (Oliver, 1999). It thus militates against "ableism," which defines value or even humanness of a person according to a predetermined average ability of body or mind (Siebers, 2008, p. 8). A key achievement of the social model has been to support a discourse for the disability movement, drawing attention to concerns of psychological and physical oppression and unequal material conditions that affect those with disabilities (Oliver, 2013).

Despite the political and scholarly discourse stimulated by a social approach, there is significant criticism that the social model has created confusion and division within studies of disability (Watson, 2012). Criticisms have been widespread including assertions that: the model fails to account for differences between those with disabilities (Morris, 1996; Wendell, 1996); the model is reductionist by removing the body from study (Hughes & Patterson, 2010); and it "over socialize(s) the phenomenon of disability" (Reindal, 2008, p. 142). Oliver (2013) argued that one reason for these criticisms may be narrow interpretations of the social model and its applicability, and inadequate development of the model since it was first developed in the 1980s.

### **2.2.2 The Social Relational Model of Disability**

Within this context, Carol Thomas and others have sought to introduce into the social model a corporal aspect. In her social relational model, Thomas (2010, p. 37) identified “impairment effects” which result from a physical or intellectual condition or illness and are separate from social effects. These effects include a lack of physical mobility or cognitive ability, and/or pain and fatigue which are experienced in a unique manner by the individual. At the same time, Thomas has identified two forms of socially-created barriers which exert a significant impact on the lives of those with impairments. First, *barriers to doing* are “barriers to agency, primarily (but not limited to) physical barriers and socioeconomic exclusion” (Hanisch, 2014, p. 211). An example might be when an individual with a mobility impairment is unable to access public space because the building lacks an accessible entrance or the individual does not own a mobility device. Second, *barriers to being* refer to psycho-emotional elements that impact an individual’s sense of self. For Thomas, barriers to being are often the result of conscious and unconscious psycho-emotional disablism that may occur in relationships with family, community and helping professionals (Watson, 2012).

Reindal (2008, 2009, 2010) has added into the social relational model a capability approach based in the work of Amartya Sen and Martha Nussbaum. It is influenced by the earlier work of Buchardt (2004) who argued that disability may be seen as capability-poverty. Capabilities are commonly equated with the freedom to choose a form of life or type of functioning, and have as their goal the enhancement of human dignity (Nussbaum, 2006). The capability-poverty of disability relates to the limitations an individual with a disability experiences in making choices about their life and in meeting the potential they envisage for themselves (Reindal, 2010). For Reindal, socially-created oppression, deprivation and discrimination lie at the root of the capability-poverty of disability.

Reindal's capability-social relational model of disability addresses many of the criticisms of the social model, including its disproportionate focus on social constraint, and its failure to account for individual difference and the experience of corporal impairment. Reindal's model starts with the unique individual, including their personal resources and challenges. From this position, the model emphasizes individual capabilities, not as ends themselves nor to serve a broader political agenda, but rather as a means of supporting human dignity. Despite this focus on the individual, the model does not ignore or diminish the role of oppressive social structures and discourses, particularly in the ways that they create barriers to "doing" and "being." Thus, a central goal of the capability-social relational model is the creation of social conditions that will support individual flourishing for all, including those with disabilities (Reindal, 2009).

### **2.2.3 The Social Relational Model and Childhood Disability**

Early attempts to develop childhood models of disability have been variously criticized on multiple accounts, including for their reduction of children to "victims" rather than those with voice and agency (Watson, 2012). Recent studies have suggested the appropriateness of social relational models in helping to account not only for corporal impairment but also the unique barriers to a positive sense of self experienced by children and adolescents with various disabilities. For example, Sylvester, Donnell, Gray, Higgins, and Stalker (2014), in a study of 91 Scottish children with disabilities, worked within the social relational model to identify specific barriers to doing and being. The former ('doing') included a lack of funding to support inclusion in recreational activities and the latter ('being') included a lack of community belief in the adolescents' academic potential. Similarly, Snodden and Underwood (2014) used a social relational model to identify unique corporal barriers and social oppressions experienced by deaf children.

## 2.2.4 ADHD and the Social Relational Model of Disability

Although in Canada, ADHD is generally considered to be a disability that results in broad functional impairment, it is largely an invisible disability (Barkley, 2013). One apparent result is that few studies have discussed the applicability of disability models to the experience of ADHD. One study that did so, however, was that of Gallichan and Curle (2008), who interviewed 12 young people regarding their social context and coping with ADHD. The authors found links between the social model of disability and their findings given, for example, that participants felt “disabled” when they were over constricted within rigid social frameworks and conversely “felt more motivated to expend effort... if they felt that others were taking steps to be adaptable and to support their efforts” (Gallichan & Curle, 2008, p. 358). The authors found that the most relevant social effects were the “reciprocal” relationships of the individuals with ADHD and their social environment. It is notable that this study was undertaken contemporaneously with the development of the social-relational model, raising the question of whether the authors may have explored its applicability to their work had they been aware of it.

ADHD also has been parenthetically discussed within critical disability studies, as an example of a condition whose recognition has been affected by historical and social conditions. Nonetheless, Shakespeare (2013) argued that despite any resulting risk of misdiagnoses, “it is very dangerous indeed to consider that this means impairments (such as ADHD) do not exist or do not matter” (Shakespeare, 2013, p. 69).

Although the number of studies which discuss disability theory in the context of ADHD is limited, the implication of those that do is that ADHD before adulthood may best be understood through a capability-social relational model. On one hand, following Shakespeare (2013),

Barkley (2013) and others, ADHD is viewed as a corporal condition that creates impairment effects, including those related to cognition, learning and social behavior. On the other hand, following studies such as that of Gallichan and Curle (2008), ADHD is seen as highly affected by social factors, including the provision of educational and other supports, and social norms and relations. These studies underline that the relationship between an individual with ADHD and their social environment appears to highly influence their self-identity, self-esteem, and ability to flourish, including setting and reaching goals.

### **2.2.5 Disability Theory Summary**

Given the above considerations, in this study I have adopted a capability-social relational model. The study is premised on the assumptions that an adolescent's experience of ADHD is affected both by impairing effects of their condition and other resilience-promoting/depleting personal resources and/or challenges in their environment. Accordingly, an adolescent will be affected by broad social forces, including resource allocation and social relationships that variably may be empowering and/or disempowering. Both the personal and social influences affect the individual's capability to experience human dignity and flourishing. Notably, this model allows for acceptance of constraints of the socio-economic and political environment on an individual with ADHD. At the same time, following Ungar (2008) and Masten (2014a, 2014b), it enables recognition of their potential, when able, to navigate within and influence their environment.

### **2.3 Anti oppressive Social World**

Similar to the development of social and social-relational models of disability, the anti oppressive framework developed in response to a "pathologizing and individual-focus" which

dominated social work practice until the 1960s and 1970s (Hick, 2002, para. 3). Influenced by various schools including Indigenous, anti-race and feminist scholarship, anti oppressive approaches identify that “oppression is at the core of social problems” (Baskin, 2002, p. 6). Key insights for social work practice and scholarship include concern that problems experienced at a personal level are often causally linked to social conditions and that institutions, social relations and discourses often create and perpetuate discrimination against oppressed groups, for example, through pathologizing the challenges they are experiencing (Baines, 2007; Mullaly, 2002).

Given this discursive context, a goal of anti oppressive social work is a fundamental change of social structures. A key influence in this regard has been the work of Brazilian educator Paulo Freire, whose theory of conscientization envisages processes by which oppressed individuals come to understand oppressive structures in their lives and engage in reflexive praxis that transforms them as agents of change (Freire, 2007). In addition to this structural focus, anti oppressive social work seeks change at an individual level, including by tangible measures to reduce material inequality and by support that addresses the “psychological consequences of oppression” (Mullaly, 2002, p. 249) experienced by individuals and families.

Like the social and social-relational models of disability, anti oppressive social work research and practice highlight the role of social structures in creating and perpetuating oppression, including at psychological and material levels. A key influence on the current study was Freire’s (2007) work, which describes the way that these structures may adversely impact individuals and communities; yet, at the same time, Freire argued that these structures can become the focus and site at which individuals and communities achieve ameliorative social change.

## Chapter 3: Literature Review

### 3.1 Understanding ADHD

#### 3.1.1 ADHD: Diagnostic Criteria and Characteristics

Although the subject of a significant body of research, numerous controversies remain in the literature and in practice regarding ADHD, including concern that it is over-diagnosed and often mistaken for other conditions (Dwivedi & Banhatti, 2005). According to the fifth edition of the *Diagnostic and Statistical Manual (DSM-5)*, individuals with ADHD have persistent patterns of inattention and/or hyperactivity-impulsivity. These patterns interfere with day-to-day functioning and/or long-term development (American Psychiatric Association, 2013). According to the DSM-5, ADHD affects between 2-7% of the population and a recent Canadian study identified a 5.4% prevalence rate (Hauck, Lau, Wing, Kurdyak, & Tu, 2017). To receive a diagnosis of ADHD, an individual must have demonstrated 6 (as a child), or 5 (as an adult), inattentive or hyperactive-impulsive symptoms, for a minimum of 6 months.

Table 1

*Selected Symptoms of ADHD*

<u>Inattentive</u>	<u>Hyperactive-Impulsive</u>
Failing to give close attention to detail	Fidgeting with hands or feet, and/or standing when sitting would be expected
Not listening when spoken to directly	Unable to take part in recreational activities at an appropriate pace and tone of voice
Avoids or dislikes activities that require sustained mental attention	“On the go” as if being driven by a “motor”
Fails to start or complete common school or work, household tasks	Excessive talking

*Note.* Males are approximately 2 times more likely to be diagnosed with ADHD than females.

(Center for Disease Control and Prevention, 2018)

Although 20-30% of adults report minimal or no impairment due to ADHD symptoms, it is considered a chronic, lifelong condition for the majority (Barkley, 2013). While symptoms usually emerge between 3-6 years of age, there are increasing reports of ADHD having first onset in adolescence and early adulthood. However, caution has been urged, in that some of these cases may actually be other conditions such as the impacts of substance abuse (Murray, Eisner, Obsuth, & Ribeaud, 2017; Sibley et al., 2017). While there is variability in reported rates of ADHD in different countries and even across regions in Canada, it is believed that ADHD diagnosis rates are increasing (Rochester, Bolden & Kwiatowski, 2018).

### **3.1.2 Classification of ADHD**

ADHD is, like Autistic Spectrum Disorder (ASD), considered a neuro-developmental disorder (Sridhar, Bhat, Acharya, Adeli, & Bairy, 2017). It is considered polygenic due to the “addictive effect of genes affecting... neurotransmitters” (Sridhar, Bhat, Acharya, Adeli, & Bairy, 2017, p. 94). ADHD has most commonly been associated with altered functioning in the frontal lobe, dopaminergic and noradrenaline systems (Kofler, Irwin, Soto, Groves, Harmon, & Sarver, 2018; Viera de Melo, Trigueiro, & Rodrigues, 2018). However, there is increased recognition that it is better considered as a multi-network disorder that affects multiple areas and neurochemicals within the brain, resulting in a broad range of functional impairments in cognition, emotional regulation, motor functioning, sensory-perception, and social skills (Viera de Melo, Trigueiro, & Rodrigues, 2018).

Despite long-standing research, there remains significant debate regarding the key neurocognitive deficits that are associated with ADHD. Recent studies have underlined that, although ADHD historically has been identified as a largely homogenous disorder in which one or several core deficits were sought, it should more appropriately be considered a heterogenous disorder which affects children and adolescents differently in varying areas of their lives, including academics, social functioning, and family life (Kofler et al., 2018). Relatedly, Chacko, Kofler, and Jarret (2014) reviewed the literature and identified eight common conceptual models for ADHD. The models vary in terms of what they identify as the central deficit or deficits of ADHD, including sustained attention, processing speed, working memory, behavioral inhibition, and deficits in the ability to maintain state regulation. An additional key area of debate is whether ADHD should be understood to result in acquisition deficits, for example, related to social skills, or whether the condition should more appropriately be understood as related to performance deficits, namely an ADHD-related inability to apply skills and information (Aduen et al., 2018).

### **3.1.3 Causes of ADHD**

ADHD is believed to have a heritability rate as high as 75% (Cetin & Isik, 2018). The implicated genes are believed to influence the structure and function of the brain, including an underactive and smaller than average sized pre-frontal cortex (Aduen et al., 2018). Puddu, Rothhammer, and Rothmanner (2017) argued that resulting traits, including impulsivity and hyperactivity, may have been adaptive in ancient hunter-gatherer societies, yet may now, in modern society, be disadvantageous. Genetic factors may be more influential in the inattentive than hyperactive/impulsive forms of ADHD (Stergiakouli et al., 2015).

While genetic influences are believed to be the dominant cause of ADHD (Rydell, 2017), environmental factors also have been found to be causal in its development. These include prenatal exposure to toxins, including through cigarette smoking, alcohol and drug use in the birth mother (Eichler et al., 2018; He, Chen, Zhu, Hua & Ke, 2017; Sandtory et al., 2018), and exposure to other environmental toxins, such as lead and poly-aromatic carbons that are common in air pollution (Perera et al., 2018), insecticides (Fage-Larsen, Anderson, & Bilenberg, 2017) and bisphenol A (Rochester, Bolden, & Kwiatkowski, 2018). The long-term use of acetaminophen by birth mothers during pregnancy has also been associated with increased rates of ADHD (Ystrom et al., 2017). Malnutrition has also been found to be associated with higher rates of ADHD (Gallery et al., 2012), as has iron deficiency (Islam et al., 2018). Children born to mothers younger than 20 years of age are more than 3 times as likely to have ADHD, compared to those born to mothers over 25 years of age (Pohlabeln, 2017). After birth, exposure to environmental toxins such as lead has been found to increase rates of ADHD, as has experiencing a brain injury (National Institute of Mental Health, 2018).

Environmental influences have led researchers to identify several social conditions that may be correlated to ADHD, including maternal stress and hardship (Loomans et al., 2011; Perera et al., 2018; van den Bergh et al., 2006) and parental poverty (Rowland et al., 2018). Researchers have also reported higher rates of ADHD in children who have experienced adversity, including those in care (Willis, Dhakras, & Cortese, 2017), certain groups of adopted children (de Maat, Knuiman, Rjik, Hoksbergen & Van Baar, 2018; Milner, Pitula, Kossand, & Gunnar, 2015) and those who have experienced or witnessed domestic violence (Lewis et al., 2015).

### **3.1.4 Comorbidities and Risks of Adverse Outcomes**

**Neurological, Mental Health and Physical Health.** More than half of children and adolescents with ADHD have comorbid disorders, many of which continue into and beyond adolescence (Miranda, Colomer, Fernandez, Presentacion, & Rosello, 2015). A high rate of comorbidity exists with oppositional defiant disorder (ODD) – estimates suggest that between 40-60% of children with ADHD also have ODD (Barkley, 2018; Phelan, 2017). Concomitantly, it is believed that 25-40% of children with ADHD develop more serious conduct disorders as adolescents (Barkley, 2018). Although it was previously believed that ADHD and ASD rarely coexist, there is an increasing contention of a significant overlap in symptoms and increased comorbid diagnosis. For example, in a study of 107 adolescents diagnosed with ASD, Joshi et al. (2014) found 76% also met diagnostic criteria for ADHD.

A “significant minority” of individuals with ADHD are at increased risk compared with neurotypical peers of developing mental health disorders in later life, including rates of 25% for depression and 5-10% for more serious mental health disorders such as bipolar disorder (Barkley, 2013, p. 3). There is also an increased risk of several physical health disorders among adults with ADHD, including obesity, asthma, and sleep disorder (Instanes, Klungsøyr, Halmøy, Fasmer, & Haavik, 2018). Also noted in the literature is the relationship between ADHD and elevated risk of non-intentional injury in children and adolescents (Ruiz-Goikoetxea, 2017), motor vehicle accidents (although this is reduced by regular medication use) (Chang et al., 2017), and premature death (Dalsgaard, Østergaard, Leckman, Mortensen, & Pedersen, 2015; Hechtman et al., 2016).

**Smoking and Substance Abuse.** It is believed that 40-50% of children and adolescents with ADHD will, by the time they are adults, be regular nicotine users (Molina, 2011). There is also a link between substance abuse disorder (SUD) and ADHD. Estimates suggest that 15-25%

of individuals with SUD also have ADHD (Wilens, 2011), and that at least 1 in 5 adults with ADHD will experience SUD. ADHD increases challenges to the treatment of SUD, including being correlated with higher rates of remission, and concomitantly, SUD negatively affects the diagnosis of ADHD (Wilens & Upadhyaya, 2007). A recent study reported that only 3% of Canadian inmates self-identified as having ADHD, however a systematic review of 42 studies involving 15 countries, including Canada, found rates of 26% within incarcerated populations (Young et al., 2015; Hesson & Fowler, 2018).

**Employment and Education.** Individuals with ADHD are at heightened risk for a learning disability (LD). While the estimated rate for LD in Canada is 3%, it is believed that 25-40% of individuals with ADHD have a LD (Turcotte, 2015; Barkley, 2018). Even without a diagnosed LD, individuals with ADHD are at increased risk, relative to their peers, of academic underachievement, including being more likely to drop out of school, to fail a grade, to be suspended or expelled, and to have a lower grade point average (Hechtman et al., 2016; Kent et al., 2011). They are also significantly less likely to obtain higher level education (Hechtman et al., 2016). In a longitudinal study of 476 adults who had been diagnosed with ADHD as children and 271 peers not similarly diagnosed, significant differences were found on occupational outcomes, including decreased average job length and current income and increased number of times fired or quit among those with ADHD (Hechtman et al., 2016). Notably, whereas 3% of the participants without ADHD were receiving social assistance, 16% of those with ADHD were found to be receiving assistance (Hechtman et al., 2016).

### **3.1.5 Social Relations**

Children and adolescents with ADHD often experience social challenges, including rejection from peers due to various causes such as peers' negative perceptions of disruptiveness, self-centeredness, and aggressive behavior (Zambo, 2008; Ben-Naim, Marom, Krashin, Gifter & Arad, 2017). Children and adolescents with ADHD are at increased risk of both being bullies and experiencing bullying (Unnever & Cornell, 2003). Longitudinal studies of adults diagnosed with ADHD as children suggest that most continue to experience social impairment into adulthood (Hechtman et al., 2016). Factors such as restlessness, sleeplessness, time management difficulties, impulsivity, and a need for stimulation can lead to increased risk of marital conflict and breakdown, and dysfunctional parenting (Ben-Naim, Marom, Krashin, Gifter & Arad, 2017; Jerome, 2016). ADHD is associated with riskier sexual behavior, including having sexual intercourse at a younger age, more sexual partners, and an increased number of children by the age of 18 years (Hechtman et al., 2016). Males with ADHD who are problem drinkers are at a heightened risk of perpetrating intimate partner violence (Wymbs et al., 2017). Adolescents with ADHD are at increased risk of involvement with the criminal justice system (Bussing, Mason, Bell, Porter, & Garvan, 2010).

### **3.1.6 Societal Impacts of ADHD**

Although understudied to date, increasing attention has been devoted to the social costs of childhood and adolescent mental health and neurological conditions like ADHD (Casadei, Cartabia, Reale, Costantino and Bonati, 2017). For ADHD, costs may be assessed both for supportive services, including health care and educational resources for minors, and for the broader range of social costs related to adult ADHD, for example, loss of employment and criminality. No Canadian studies were found that comprehensively addressed either category; however, several studies exist in similarly developed countries. Regarding childhood and

adolescent costs of ADHD, Telford et al. (2012) found that average medical and educational costs for a UK adolescent with ADHD were \$9,300 (CAD) above those costs for a neurotypical adolescent. Casadei, Cartabia, Reale, Costantino, and Bonati (2017) found that the average additional first year costs for diagnosis and treatment of an Italian child or adolescent with ADHD, was \$2,100 (CAD). Regarding adult costs, Doshi et al. (2012) estimated the annual cost related to ADHD in the United States at \$105 - 194 billion, primarily related to low productivity and loss of income. They found that adult costs were approximately 2.5 times higher than child costs. Additional costs for adults included treatment for ADHD and comorbid conditions, costs associated with accidents involving those with ADHD, and correctional services (Swensen et al., 2003). Among other findings, the studies underlined the need for adequate, cost-effective services for children and adolescents with ADHD and their families that support positive adjustment to adulthood (Chorozoglou et al., 2015).

### **3.1.7 Family Relationships and ADHD**

In addition to the personal effects and general social costs of ADHD, the condition is believed to significantly affect and be affected by the family. With regard to its impacts on families, ADHD has been found to have a bearing on parenting stress, namely, the stress incurred as parents recognize that the demands upon them exceed their personal resources (Deater-Deckard, 1998). For example, in a meta-analysis and systematic review, those parenting a child or adolescent with ADHD were found to experience significantly more stress than parents of a child or adolescent without ADHD (Deault, 2010; Theule, Wiener, Tannock, & Jenkins 2013). This may relate to increased caregiving demands, including a child not following through on tasks or not obtaining typical levels of independent functioning. Parenting demands further relate to a larger than average number of medical appointments and greater need to engage in conflict

resolution with siblings and institutions such as schools. In their meta-analysis, Cheung and Theule (2016) found that parents of children with ADHD were at increased risk (2.85 times) for a mental disorder than those parenting children without ADHD. Notably, recently there has been increased attention to the relative experience of parenting a child with ADHD as compared with other disorders. In their comparison of families of children with anxiety disorder, ADHD and ASD, Telman, van Steensel, and Maric (2017) found increased rates of parental stress and psychopathology in families with ADHD and ASD.

Families of children with ADHD have reported higher levels of conflict than non-ADHD affected peers (Markel & Weiner, 2014), higher than average rates of parental frustration (Mitchell and Climie, 2017), and increased rates of marital breakdown (Wymbs et al., 2008). In a study of 476 children with ADHD and their siblings (n=337) (which controlled for carers' and siblings' own ADHD symptoms), Peasgood et al. (2016) found that siblings reported lower happiness with their family and life, which they argued might relate to an increased number of experiences of bullying within the family. Siblings reported receiving less attention and differential discipline than their affected brothers and sisters, and becoming parentified regarding their care (Salmeron, 2008). For parents, the impact of ADHD on mothers may be more pronounced than on fathers, given that they generally function as primary caregivers (Cheung, Aberdeen, Ward & Theule, 2018).

Family environmental factors may also influence the nature and severity of ADHD symptomology in children and adolescents. In their recent study of 324 middle school adolescents with ADHD, Ray, Evans, and Langberg (2017) found higher rates of various conditions including depression in cases where a two-parent family had broken down and the child was now part of a one parent, step or blended home. In addition, Heckel, Clarke, Barry,

McCarthy, and Selikowitz (2009) found increased symptom severity from ADHD in children and adolescents who experienced family breakdown. Higher parenting stress and parenting approaches such as inconsistent discipline are also correlated to severity of ADHD symptoms (Li & Lansford, 2018).

Given these effects and challenges, and particularly its strong hereditary components, ADHD has been described as having a “familial” nature (Biederman, 2005, p. 1216). It may be best understood through a developmental-transactional framework that recognizes that both parents and children contribute to family quality of life, and that family relationships are dynamic and evolving (Johnson & Chronis-Tuscano, 2015).

### **3.1.8 Treatment Approaches**

The Canadian ADHD Resource Alliance’s (CADDRA) Practice Guidelines and the Center for ADHD Awareness in Canada (CADDAC) recommend a holistic strategy or multi-modal approach to treatment that involves five parts: education for the patient with ADHD and family, behavioral or occupational interventions, psychological treatment, educational accommodation and medical management (Canadian ADHD Resource Alliance, 2018; Center for ADHD Awareness in Canada, 2018). This holistic approach is in line with other similarly-situated countries, including the United Kingdom (National Institute for Health and Care Excellence, 2018), and places a greater emphasis upon non-pharmacological interventions than guidelines in the United States. Recent research suggests that further attention and study are needed regarding the nature and delivery of education to parents regarding ADHD and supportive interventions (Henley and Climie, 2018).

A concern in the literature is that, despite practice guidelines such as those of CADDRA, medication is the most common front-line treatment for ADHD and may be overprescribed (Hoekstra and Dietrick, 2014). The literature is clear that ADHD medications are effective in improving symptoms of ADHD in the majority of cases (Dalsgaard, Nielson, & Simonsen, 2014). Nonetheless, concern has been raised that both ADHD and non-ADHD medications may be overprescribed to those with ADHD at the expense of other treatment approaches, including parental training, counselling, and accommodations at school (Hauck, Lau, Wing, Kurdyak, & Tu, 2017).

### **3.1.9 Differential Outcomes in Children and Adolescents with ADHD**

Despite the risks associated with ADHD, it is estimated that 60% of those with the condition experience intermediate emotional, educational and social adjustment, and 20% experience positive outcomes (Spencer, Biederman, & Mick, 2007). With regard to the latter, one area of emerging research has examined the association between ADHD symptoms such as risk-taking and success in careers involving innovation and entrepreneurialism (Thurik, Khedhaouria, Torrès, & Verheul, 2016). However, given that the study of factors associated with risk and resilience in those with ADHD is “in its infancy,” little is known about what factors, if any, contribute to these positive outcomes (Climie & Mastoras, 2015; Dvorsky & Langberg, 2016, p. 372).

The one systematic review found in the literature, which addresses resilience in adolescents with ADHD, found that past research has focused upon risk factors, including parental psychopathology and comorbid mental health concerns (Dvorsky and Langberg, 2016). Using a developmental psychopathology framework, Dvorsky and Langberg (2016) identified 31 studies

of adolescents under 18 years with ADHD that examined resilience promoting or protecting factors at an individual, family and social/community level. For individual factors, they identified “positive self perceptions of competence” (Dvorsky & Langberg, 2016, p. 327) as both promotive and protective in studies of adolescents aged 11 years and older. Academic enablers such as study and motivation had only a mixed effect on positive academic outcomes, while social skills were not found to support positive academic outcomes. The latter may relate to findings in other studies suggesting that: (a) social functioning in ADHD is impeded by an inability to perform acquired social skills rather than an inability to acquire such skills (Aduen et al., 2018); and (b) children and youth with ADHD experience challenges in applying emotional intelligence knowledge in natural settings (Climie, Saklofske, Mastoras, & Schwean, 2017).

In an article published after Dvorsky and Langberg’s (2016) review, Schei et al. (2018) identified personal efficacy and perceived sense of control as protective factors for resilience in adolescents transitioning to adulthood. Other factors that have been found to support the resilience of adolescents with ADHD include access to adequate exercise (Dehkordian, Hamid, & Beshlideh, 2017). Notably, the latter factor may be considered both personal and/or relate to an individual’s access to material resources.

Dvorsky and Langberg (2016) found greatest support at the family and social level for protective and promotive factors for resilience. Regarding family factors, they identified nine studies which identified positive parenting, including maternal affection and authoritative parenting, as either a promotive or protective factor for resilience. While most samples in the reviewed studies involved early childhood, two studies identified positive family environments, including cohesion, as promotive and protective for older adolescents. In addition to studies identified in Dvorsky and Langberg’s (2016) review, factors that have been found to support

positive development include mindful parenting (Dehkordian, Hamid, & Beshlideh, 2017) and the positive involvement of fathers in children's lives (Mitchell & Climie, 2017). This may include parenting which operates from an acknowledgement and acceptance of disability (Barkley, 2013).

Regarding social factors, Dvorsky and Langberg (2016) identified four longitudinal studies that demonstrated an association between positive adjustment for adolescents with ADHD and the presence and quality of friendship and peer acceptance. Notably, social acceptance was the most strongly associated protective factor against the development of depressive symptoms (Dehkordian, Hamid, & Beshlideh, 2017), and was a protective factor for academic performance (Dvorsky, Langberg, Evans, & Becker, 2016). Similarly, in their study of 55 children with ADHD aged 8-11 years, Mastoras, Saklofske, Schwean, and Climie (2018) found a notable association between perceived social support and self-esteem, suggesting potential stability in the importance of this factor for resilience in developing minors. Other studies have described the importance of school-based factors, including a positive relationship with and support from teachers (Schei et al., 2018).

Climie and Mastoras (2015) recommended further strengths-based research for children and youth with ADHD in order to develop understanding about "what protective factors may be most influential" (p. 297) and what are "the most effective approaches through which to implement strengths-based and positive psychology-grounded interventions" (p. 297). They noted the need for such research to be coordinated "across levels of research and practice" (Climie & Mastoras, 2015, p. 297). Notably, in completing this literature review, no studies were found which explored resilience in adolescent ADHD from within the field of social work;

additionally, there were few qualitative studies across fields of practice which explored the complexity of ADHD-related experience.

### **3.1.10 Summary of Relevant ADHD Research**

Although ADHD is considered one of the most researched childhood disorders, the primarily quantitative research completed to date has largely focused on its physical pathology, including ways in which ADHD impacts brain structure, and the efficacy of different pharmaceutical interventions. Despite this research, significant questions remain, including uncertainty about central challenges that ADHD creates for individuals and approaches for coping with ADHD when medication is either not being used or is not active in the individual's system. Overall, this research increasingly recognizes the diversity and complexity of how ADHD is manifested and the spectrum-like nature of the disorder.

Regardless of its etiology, empirical evidence identifies significant, persistent risks from ADHD for physical and mental health, and social functioning. This includes its potential impact on family life and associated risks for parental stress and the development of additional disorders and challenges for siblings and parents. Although practice guidelines advocate a holistic approach to intervention, there is concern that pharmaceutical treatment is prioritized which creates additional risks for adolescents with ADHD also, for example, creating serious side effects for some individuals (Meppelink, Bruin, & Bogels, 2016).

This research points to the need for further exploration of the factors or elements which, in addition to the appropriate use of medication, promote resilience and moderate risks associated with ADHD. In this light, Barkley's research on ADHD is notable in identifying that more than half of those with ADHD do not develop significant challenges in later life (Barkley, 2013).

Preliminary research suggests that these outcomes may relate to personal factors such as positive self-concept, but are also importantly affected by family level factors such as positive parenting and family cohesion, and environmental factors like positive social and school relationships (Dvorsky & Langberg, 2016; Mastoras, Saklofske, Schwean, & Climie, 2018; Mitchell & Climie 2017). This strengths-focused research suggests a need for further study, including at the family and community level, in elucidating core elements and processes that may support resilience in adolescents with ADHD.

## **3.2 Emerging Adolescence**

### **3.2.1 Theories of Adolescence and Early Adolescence**

Adolescence is commonly understood to be the “developmental period from the onset of puberty until the transition to adulthood as marked by marriage, parenthood, completion of formal education, financial independence from parents or a combination of these milestones” (Banati & Lansford, 2018, p. 3). It is considered a “demographically dense” period of life, given the significant number of changes that occur that may affect both current and later health and development (World Health Organization, 2018). Notably, parents are often concomitantly experiencing physical and cognitive changes associated with their own aging processes during their child’s adolescence (Weymouth & Buehler, 2016).

Early adolescence is typically marked by physical changes, including a growth spurt and the development of sex organs and secondary sex characteristics; significant neurological change also occurs. In males, the latter changes tend to start later and last longer than in females, marked by a “tendency to act impulsively and be uncritical in...thinking” (UNICEF, 2018, p. 6). Early adolescence is commonly thought to occur between the ages of 10-14 years but can start earlier

and end later. It is considered a “turning point” for the development of several psychopathologies in later life, including depression (Babore, Trumello, Candelori, Paciello, & Cerniglia, 2016) and aggressive symptoms that can be linked to the subsequent development of conduct disorder (Babore, Carlucci, Cataldi, Phares, & Trumello, 2017).

The life stages models of Erickson and Piaget identify a central challenge of adolescence as the formation of a personal identity, including a separation from parents (Piaget, 1970; Erickson, 1998). However, these models are increasingly criticized as counterproductive as they advance a “largely static” process based on Western norms and values, in which development is viewed as occurring in a “linear gradation” (Banati & Lansford, 2018, p. 5). Accordingly, while adolescence involves a transition to adulthood from childhood, there is increasing recognition that how and when this occurs are affected by structural factors including socioeconomic experiences and culture. Contrary to early models like Hall’s (1904) *Storm and Stress* theory, research now suggests that most adolescents transition to adulthood with few notable challenges, maintaining strong relationships with their families. Nonetheless, certain adolescents are considered to be “at risk” of adverse outcomes due to personal factors such as disability and addiction, and/or environmental circumstances such as homelessness and low socio-economic status.

### **3.2.2 Parent-Child Relationships in Emerging Adolescence**

Parents play a key role in adolescent behavior, which appears related both to adolescents’ “perception of their parents’ behavior” and to the “quality of their interactions with them” (Babore et al., 2016, para. 6). Factors that support a positive relationship between an adolescent and parent include a warm, authoritative parenting style and either no, or well controlled,

parental mental health pathology (Babore et al., 2016). Moderate levels of conflict between adolescents and parents are considered normal in supporting an adolescent's development of personal identity as separate from the family, and for family reformation (Bornstein & Putnik, 2018).

However, beyond these moderate levels of conflict, some families experience an increase in parent-child hostility in early adolescence, including arguing, yelling, and verbal and physical aggression (Weymouth & Bourne, 2016). High rates of parent-child hostility are associated with higher rates of adolescent risk for various physical and mental health conditions (Weymouth & Bourne, 2016). Factors that appear to contribute to higher rates of hostility include intrusive parenting styles, lack of social support for the family unit, and adolescent emotional dysregulation (Weymouth & Bourne, 2016). It is notable that the latter is a symptom of ADHD.

### **3.2.3 Attachment and Emerging Adolescence**

Although it is often associated with early childhood, attachment remains a key factor in adolescent development. Attachment styles learned in childhood remain largely stable over the life course, and the experience of feeling loved and secure is believed to continue to support positive development in adolescence (Strauss, 2018).

During the last 20 years, attention has been given to the relationship between attachment, parenting relationships and ADHD. Much of the research has focused specifically upon the relationship between mothers and their same or opposite gender children (Anderssen, Hinshaw, & Simmel, 1994; Harold et al., 2013; Gau & Chang, 2013). Studies are also increasingly examining the differential role of both male and female attachment and parenting styles on children and adolescents with ADHD (Al-Yagon, Forte, & Avrahami, 2017). For the purposes

of this current study, there are two key findings in the research. The first is that the nature of parent-child relationships and attachment varies according to complex factors, including gender, age, maturation, identity and personality, ethnicity, and culture (Bornstein & Putnick, 2018). The second is that various symptoms of ADHD, such as impulsiveness, disorganization, and defiance can contribute to challenges in parent-child relationships. However, the experience of attachment remains equally if not more important for the positive development of adolescents with ADHD as their neurotypical peers, given experiences such as stigma and social exclusion, discussed above.

### **3.2.4 Summary of Emerging Adolescence Literature**

Emerging adolescence is a distinct stage of adolescence marked by the emergence of the physical changes of puberty and social changes such as possible increased parent-child conflict. Several ADHD symptoms, including emotional dysregulation, can create barriers to positive development. For example, ADHD-related symptoms can contribute to increased stress in parent-child relationships, impacting attachment.

To date, most research on ADHD has focused upon young children and older adolescents. Mastoras, Saklofske, Schwean, and Climie (2018) identified a need for research on adolescents with ADHD that focuses upon the period of development when “internalizing problems may become more prominent” (p. 721). As noted below, the current study has built upon the recommendation of Mastoras et al. (2018) by seeking to understand in more depth the challenges and areas of potential growth in emerging adolescence.

### 3.3 The Need for this Study

Despite decades of research regarding the nature of ADHD and its symptoms, the literature demonstrates that those with ADHD and their families continue to report significantly lower quality of life relative to neurotypical peers, and that they remain at increased risk for adverse outcomes. Additionally, ADHD has continued to result in significant societal costs, including those related to unemployment and criminality for adults who have received inadequate support for their needs (Knecht, de Alvaro, Martinez-Raga, & Balanza-Martinez, 2015; Kotsopoulos, Connolly, Sobanski, & Postma, 2013).

While the majority of research has been deficit focused, there is increasing awareness that a portion of those with ADHD and their families experience positive life outcomes. This small but emerging body of research exploring resilience in ADHD suggests a myriad of factors that may contribute to these positive outcomes. For instance, a positive parenting approach and family-based stability and support appear to moderate the effects of ADHD in daily life and across multiple domains of life.

The gaps in the literature suggest further exploration of factors that support resilience in ADHD, including family and ecological factors, is warranted. Furthermore, there is a need to advance such knowledge in the relatively understudied area of emerging adolescence. Accordingly, as adolescent identity is forming, families may be at risk of increased conflict, and adolescents at heightened risk of co-morbid mental health conditions (Babore et al., 2016; Babore et al., 2017; Weymouth & Buehler, 2016).

Given that the limited literature in this area to date has been largely quantitative, there is a need to explore ADHD resilience in emerging adolescence in a way that prioritizes the voice and

experience of those most closely affected – adolescents, parents, and service providers. To this end, this study was designed to elicit understanding about resilience in the lives and development of emerging adolescents with ADHD and those who provide direct support to them.

### **3.4 The Goal of this Study and Research Questions**

The aim of this study was to explore the nature and elements of personal and family resilience relative to emerging adolescents with ADHD. When I began this study, I hoped it would yield knowledge regarding the ways that emerging adolescents with ADHD and their parents/caregivers understand what resilience is, what contributes to it in their lives, and how they may be supported in nurturing resilience. A priority was to amplify the voices closest to these issues, namely, emerging adolescents, their caregivers, and professionals providing direct services to these adolescents. Furthermore, I sought to develop knowledge that might inform service providers such as social workers, counsellors, school staff, personnel at spiritual organizations and supportive programs. I also wanted to undertake research to help policy makers understand and support the personal and familial resilience of adolescents with ADHD and their families. Further, I hoped that findings would support adolescents with ADHD and their families to better understand resilience and to nurture it in their lives. Finally, I hoped that knowledge acquired through this study might contribute to the academic literature in this relatively understudied area.

To achieve these aims, the three questions explored in this study were:

1. How do emerging adolescents with ADHD, their caregivers, and supportive professionals understand what resilience is and how it is experienced for emerging adolescents with ADHD?

2. What personal and intrafamilial factors do emerging adolescents with ADHD, their caregivers, and supportive professionals believe contribute to the resilience of these adolescents and their families?
  
3. In what ways do emerging adolescents with ADHD, their families, and supportive professionals believe personal and intra familial resilience may be supported and strengthened?

## **Chapter 4: Methodology**

### **4.1 Theoretical Foundations**

The research paradigm should be congruent with the aims of the study and the researchers' "beliefs about the nature of reality" (Mills, Bonner, & Francis, 2006, p. 2). In this study, two philosophical influences were important. The first was social constructivism, which "assumes that people construct the realities in which they participate" (Charmaz, 2006, p. 187). An implication is that within the research process, there is a dynamic interaction between the researcher and participant, through which "multiple realities are possible and are constructed" (Charmaz & Belgrave, 2002, p. 349). A second influence was anti oppressive, critical approaches which recognize that "oppression is at the core of social problems" (Baskin, 2002). A goal of critical social work research is to improve the representation of groups served by social workers, for example, by advancing "different forms of knowledge and different ways of creating knowledge" within social work research (Fook, 2003, p. 129).

### **4.2 Considerations Underlying Design Choice**

Given my goal to build knowledge in a relatively under-explored area, this was an exploratory study. The key considerations underlying the choice of design were the following: first, a design was sought that would facilitate the co-construction of knowledge by the participant and researcher second, a key aim was to respect the vulnerability of both adult and adolescent participants, with the goal of supporting their empowered engagement; finally, a design was sought that would provide a tangible outcome in the form of theory development and practice recommendations regarding improvements in support to emerging adolescents with ADHD. Given these goals, a qualitative design was used that could build upon and contribute to

the literature, hitherto based primarily upon quantitative studies. I sought to add the voice and perspective of the population of emerging adolescents with ADHD and their families. The study was facilitated by a research relationship in which knowledge was co-constructed.

### **4.3 Constructivist Grounded Theory**

Constructivist grounded theory (CGT) uses the social constructivist's "attention to context, action and interpretation with grounded theory analytics" (Charmaz, 2008, p. 408). It retains classical grounded theory's emphasis upon patterns of behavior and what Glaser and Strauss (1967) identified as incidents in the data. However, a CGT researcher does not seek a core category and overarching, conceptual framework that accounts "for as much variation in the data as possible" (Breckenridge, Jones, Elliott & Nicol, 2012, para. 8). Rather, CGT aims toward the co-construction of a more "diffuse" interpretive framework that focuses as much upon difference as similarity within the data, acknowledging in its outcomes the existence of multiple realities (Breckenridge et al., 2012, para. 12). For Charmaz, the four key elements of CGT are attention to context, social location, multiple realities, and the subjectivity of the researcher (Charmaz, 2008, p. 408).

In designing a constructivist grounded theory approach, Charmaz advocated for methodological flexibility which allows for the collection of data best suited to present participants' perspectives (Charmaz, 2002), including but not limited to semi-structured interviews. The key concern is how participants "construct meanings and actions from as close to the inside of the experience as possible" (Charmaz & Belgrave, 2002 p. 349). There is a natural affinity between CGT and the goals and practice of social work, including upholding the value of

the diversity of human perspective and experience (Creswell, 2012), and a quest to unearth and redress relational oppression, including between the researcher and participant.

Despite its potential, several important criticisms have been made of Charmaz's approach to CGT. For Glaser (2002), a key concern is its acceptance of the subjectivity of the researcher and multiple realities. He argues that, rather than empowering participants, this leads researchers towards an acceptance of bias in their research and an overemphasis upon their own rather than the participants' perspectives. Charmaz herself has identified a different criticism – namely that the movement away from core categories and overarching conceptualizations may lead researchers too far into individual experience and away from the social forces that may act upon them (2014). In responding to these criticisms, Charmaz and other theorists have clarified the researcher's role. Rather than advancing their own position, researchers use the constant comparative method to build understanding of the relationship between the participant and his or her social context, for example, situating and interpreting how a participant may have constructed their social reality through the influence of “dominant social structures and discourses” (Higginbottom & Lauridsen, 2014, p. 5).

Keeping this approach in mind, CGT was used as the research framework for this study for several reasons. First, it prioritizes the relationship between the researcher and researched as one of co-constructing knowledge, which was important, given the diverse, personal experience of resilience, including its relatedness to belief systems. Particularly, CGT permits acknowledgment of the researcher's role in interpreting the various realities experienced by the participants. Second, CGT is an effective method for not only seeking understandings of individual experience but also for identifying social issues that may influence and underpin them (Charmaz, 2017). CGT was, therefore, appropriate given a social ecological model of resilience, which

identifies both personal and ecological resilience factors, and their dynamic interaction. Finally, CGT was appropriate given its roots in pragmatism, including a focus upon process rather than the stability of relations and social structures, its understanding that there exists a dynamic relationship between meaning and action, and its assumption that an actor plays a fulsome role within his or her environment (Charmaz, 2017). As described by Charmaz (2010), it was hoped that CGT would support the asking of critical questions that might unearth diverse and unexpected experiences of oppression, including those that may exist for adolescents who experience largely-invisible disabilities like ADHD.

## **4.4 Research Design**

### **4.4.1 Initiative for the Research**

Charmaz (2003) identified “sensitizing concepts” as the “points of departure” for research, including providing background information which informs the research question and becomes a basis for analysis (p. 259). For this study, sensitizing concepts related to both the challenges of ADHD and how individuals and families within the “ADHD experience” responded to them. Generally, I observed these responses in community settings – for example through support groups of which I was a part, and communications that took place in daily life, for example, on the playground when picking up a child from school, at children’s playgroups, or during coffee hours after church. Particularly, I became aware of both the similarities and diversity within the experiences of families, and of parents’ concerns regarding gaps in services and support, including when children entered adolescence. This research became broadly focused upon families of children within this age-group, namely those exiting junior and entering middle school as this appeared to be an age of particular challenge for families that I encountered.

I originally hoped that participants in this study would be limited to adolescents and their parents/caregivers. In addition, this research had an original focus upon meaning-making and spirituality as a form of resilience. However, initial efforts to recruit sufficient participants were unsuccessful due to what appeared to be: (a) the hesitancy of many families to discuss meaning-making, spirituality, and religion; and, (2) the limited resources to undertake further adequate recruitment with adolescents and their families. Given this, the study was revised to expand participants to include supportive professionals who undertook direct service with adolescents with ADHD. This offered an additional benefit of adding a different, complementary perspective to the research. In addition, the focus of the research was expanded beyond meaning making to resilience in general in order to more effectively represent the experience and perspectives of potential participants.

#### **4.4.2 Sampling**

The purposive sample of n=20 comprised:

- emerging adolescents (aged 9-15) diagnosed with ADHD;
- the primary caregivers of emerging adolescents (aged 9-15) with ADHD;
- supportive professionals including doctors, psychologists and counsellors and educational assistants, working with emerging adolescents (aged 9-15) with ADHD.

Inclusion criteria were, therefore, that an individual was 9-15 years old and had been diagnosed with ADHD, or a caregiver or parent of, or a supportive professional providing direct service to, an adolescent who met the above criteria. Exclusion criteria included those adolescents, or the caregivers, parents or supportive professionals of adolescents, who had not received a diagnosis of ADHD from a qualified medical professional or instances when

adolescents were not informed of their diagnosis. In addition, adolescents, and their caregivers/parents and supportive professionals, were excluded if they had other conditions which affected cognition and behaviour, including global developmental delay and ASD. The primary cities for recruitment were Edmonton, Alberta and Ottawa, Ontario. In addition, given that two key national ADHD organizations, CADDRA and CADDAC, and some affiliates are in the Greater Toronto Area, recruitment also occurred through these organizations and in surrounding areas.

Originally, all eligible individuals who indicated an interest in the research were included as participants and were interviewed. As I conducted data analysis of initial interviews using the constant comparative method (Glaser & Strauss, 1967), I additionally employed theoretical sampling, resulting in ceasing to recruit supportive professionals and focusing interviews upon parent/caregiver participants, given emerging data meriting further exploration.

#### **4.4.3 Setting and Recruitment**

While most research with minors takes place within school or health care facilities, Kellett underlined the impact of institutional settings on research processes and findings (Kellett, 2011). Both conscious and unconscious relationships of power and affinity may affect both a gatekeeper's and minor's willingness to participate and the nature of their participation in research. While it may require longer time frames and more complex negotiations of social position as a researcher, situating research outside of traditional institutions of power, for example at community centers, can encourage increased levels and different experiences of comfort and openness for children and adolescents (Harris, Jackson, Mayblin, Piekut, & Valentine, 2015).

In this study, I sought to balance an awareness of the power relations inherent in medical and educational facilities, with a need to reach and communicate effectively with a dispersed population of potential participants. As such, the majority of recruitment took place within community settings, including community recreational facilities, support groups, and religious centers. To encourage diversity and geographical representativeness of the sample within the three cities, recruitment also took place by placing posters in the community-based offices of several physicians and psychologists working with adolescents with ADHD and their families. Recruitment posters were also placed in a wide range of community centers and on several Facebook pages for support groups. In order to seek as representative a sample as possible, centers which served populations characterized by economic, social, and cultural diversity were sought as places for participant recruitment. In order to post the posters, I sought approval from the organizers and administration of the program. In some cases, participants indicated they had become aware of the study through “word of mouth” within a community of supportive professionals or support groups.

Potential participants initiated contact and I then arranged either a telephone or in-person interview. At the outset of the interview, participants were provided with an overview of the research goals and process, and I informed them that I was a member of the ADHD community. I conveyed the voluntary and confidential nature of the research and their option to not answer questions that they did not choose to.

Prior to interviews occurring, consent was sought from all adult participants and the adult caregivers of minor participants through a written consent process (Appendix A). Assent was also sought from the three minor participants (Appendix B). During this initial conversation, attention was given to ensure that participants understood the voluntary and confidential nature

of the interview process, and that they understood they could choose not to respond to questions with which they did not feel comfortable. Consent was sought for a separate interview with minor participants and caregivers. Although consent was granted by the parents, two of the three minor participants requested that they take part in a joint interview with their caregiver/parent, which occurred. Each of the participants was given a \$20 gift certificate (to Chapters book store) as a token of appreciation for participation in the study. Interviews took place within community settings, such as the participants' homes, or over the telephone.

#### **4.4.4 Interview Methods**

Semi-structured, qualitative interviews were used. Questions for each interview varied according to the informant group: adolescent, parent/caregiver, and supportive professional (Appendix C). During the interview, I sought participants' descriptions of positive examples of resilience. Follow-up questions were asked in most cases regarding contrasting examples for illustrative expansion. In addition, a focus of the interview was on the factors that participants felt supported resilience – this included personal and family factors, and the ways in which these factors interacted with ecological factors. Interview questions were open ended, encouraging participants to answer to an extent and in a manner that respected their boundaries.

Interviews were audio recorded and transcribed verbatim. Transcripts were protected through encryption and password protection, and audio recordings were stored in a locked electronic device in a secure location. The only person with access to these materials was the student researcher. One additional individual, who had previously completed ethics training for graduate research, assisted with technological support for transcription. When sufficiently

audible, software was partially used to transcribe audio recordings; when audio recordings were not sufficiently audible, I transcribed interviews manually.

## **4.5 Data Analysis**

### **4.5.1 Overview of Analytical Process**

A defining characteristic of grounded theory is that it is not a linear process, but that data collection, analysis, and theory development occur throughout the research. Tweed and Charmaz (2011, p. 133) outlined the following central steps:

- developing the research questions and recruiting participants;
- employing the constant comparative method (including data collection, initial and focused coding and categorizing, theory development and memoing);
- writing up and data dissemination.

The focus of this section is the constant comparative method and how it was used to elucidate findings and develop theory.

### **4.5.2 Constant Comparative Method**

The goal of the constant comparative method is to compare data from different interviews through the research process, including “statements and incidents” within the same and different interviews to ultimately develop theoretical constructs (Charmaz, 2014, p. 54). For Charmaz, a first step is initial coding, which commonly occurs line-by-line. Data is “mine(d)” to identify the words and sentences which indicate the most important categories emerging from the research (Charmaz, 2014, p. 46). Where possible, the participant’s own words are used to develop “in

vivo” codes, “symbolic markers of the participant’s own speech and meanings” (Charmaz, 2014, p. 55). Notably, during initial stages of coding, data may begin to emerge differently than was anticipated in planning the research. As noted by Charmaz (2014, p. 46), “coding may take you into unforeseen areas and new research questions.”

A next step is focused coding, in which “theoretical integration” begins (Charmaz, 2014, p. 46). In this step, the most frequent or important initial codes are identified to “synthesize” the mass of data with the aim of developing categories (Charmaz, 2014, p. 58). This involves decisions regarding which initial codes should be discarded and retained to “make the most analytic sense to categorize (the) data most incisively and conclusively” (Charmaz, 2014, p. 57). The final step of theoretical coding refines the developing categories and relates them to each other, primarily using gerunds (Charmaz, 2014). Gerunds are action words that “not only give a sense of people’s intentions and concerns, but... also specify and anchor the analysis” (Charmaz 2008, p. 406).

Given the constructivist focus of CGT, the final step of the data analysis process of theory development focuses upon “how- and sometimes why- participants construct meanings and actions in specific situations” (Charmaz, 2014, p. 130). At this stage, the focus is on the development of one or several core categories that help to explain the pattern or process of a human phenomenon (Birks & Mills, 2011).

Through the stages of focused and theoretical coding, axial coding is used to define the subcategories of a category of data, identifying “the property and dimensions of a category” (Charmaz, 2014, p. 60). Memo writing is also used to help the researcher reflect on similarities and differences in the data, including providing a focused opportunity to reflect upon

preconceptions and explore new directions in which the data may be leading (Charmaz, 2006, p. 82). It is also a method for researchers to practice reflexivity regarding the data collection and analysis process.

### **4.5.3 Data Sufficiency**

The size of a sample in a CGT study is commonly guided by a finding of data saturation but the level of saturation may vary in range (Charmaz, 2014). Data saturation occurs when conceptual “resonance” is demonstrated, and no new theoretical categories and insights are reflected in the data (Charmaz, 2006, p. 113). In this case, it was judged that data saturation was achieved after analysis of the interviews of 21 participants, at which point new categories ceased to be identified.

### **4.5.4 Application of Data Analysis Process**

An example of the data analysis process used in this study related to the subcategory of *Shifting Identity* for parents/caregivers within the category of *Moving Forward*. During the initial review of the transcripts, initial codes emerged regarding parenting style and identity, including “overboard parent,” “not helicopter parent,” and “super involved parent.” These codes became combined into the gerund “overboard parenting” which relied upon participant language and denoted a type of parenting which was more involved than typically expected yet was qualitatively different than the meddling, hovering idea represented by the concept of “helicopter parenting.” At the same time, initial codes emerged related to a mindset parents adopted, including “rolling with the punches,” “being flexible” and “accepting the need for change.” These codes were merged into the gerund “rolling with the punches” to rely on participant language and denoted an approach to parenting which was more flexible and open to different

parenting approaches and adolescent outcomes than the parent had previously reflected. Notably, while the research question had focused upon characteristics and factors that promoted resilience, these gerunds began to indicate *a process* of becoming resilient that I had not expected as a finding from the study. At the final step of data analysis, these codes became combined in the subcategory *Shifting Identity* for parents/caregivers as they denoted the process of changing parental identity which was described in the data. I completed a memo while analyzing this code, a portion of which is included in Appendix D.

#### **4.6 Ethics**

Ethics approval for this study was obtained through the Conjoint Faculties Research Ethics Board of the University of Calgary. The critically reflexive approach to ethics (Renold, Holland, Ross, & Hillman, 2008) guided this study. This approach focuses upon both procedural safeguards and micro ethical challenges that can arise and may need to be addressed throughout the research process. For all participants, the use of consent/assent forms formed a key ethical step. Forms were completed prior to the interview and provided an opportunity for me to ensure that participants understood key considerations, including the voluntary nature of the study and the measures that would be taken to ensure confidentiality and protection of private information. These included the removal of identifying data from the final report, use of pseudonyms, and storage of interview transcripts on a locked computer in a secure area.

For the participation of minors, the key area of focus was both initial and ongoing consent and assent. In this study, the informed consent of the primary caregiver and informed assent of the adolescent was required for participation in this study. In addition, a concept of ongoing, negotiated consent by the minor participant was used. This included embedding conversations

about ethics in research discourse (Renold, Holland, Ross, & Hillman, 2008), and measures to support ongoing awareness of the participant about the research process, including placing the recording device, once turned on, in a visible location, and referring to it during the interview.

Another key ethical consideration was the risk of deductive disclosure, or erroneous identification of the interviewee. To address this, a comprehensive data cleaning process was used. This included three processes of checking data to ensure that it was non-identifiable in the final report and having a third party read the initial report to verify data appeared non-identifiable. Certain quotations were omitted in the final report as they contained potentially identifiable data. An additionally important consideration was the right of participants to consent to some but not all the research, including waiving responses to questions to which they did not feel comfortable in answering. As noted above, this was addressed through a fulsome explanation of the research procedure prior to the interview, including a reminder that the interview was a voluntary process and that participants could choose not to answer any of the questions.

A potential risk of the research was that a minor participant who was not aware of their diagnosis might become so and might feel stigmatized. As a result, a requirement for participation of the minor participants was that parents/caregivers confirmed their adolescent was aware in an age-appropriate way of his/her diagnosis. As a safeguard relative to the risk of an interview triggering upset for participants, information about counselling resources was offered to all participants if they experienced distress because of this study. Such resource was not indicated to be needed for this study.

## 4.7 Rigour

Trustworthiness relates to the credibility, transferability, dependability and confirmability of findings in a study (Guba and Lincoln, 1985). Charmaz (2006) highlighted credibility as a key concern for studies using CGT. For a study to be considered trustworthy, the onus is upon the researcher to demonstrate that it was carried out in a manner that is fair and ethical and reflects the context or experience of participants (Padgett, 2008). Commonly, a researcher uses one or more strategies and reports upon their use (Creswell and Miller, 2000).

In this study, three primary approaches for trustworthiness were used. First, the constant comparative method acted as an “in-built verification and validation” process, similar to that provided by an additional member who separately evaluates and verifies the findings of a primary researcher (Sengstock, 2014, p.182). The constant comparative method allowed me to verify findings and emerging categories against each other, and, as the literature review continued, to findings in other studies. Second, negative case analysis was sought and helped to strengthen concepts and to fill in detail regarding the relationships between categories (Ching & Martinson, 2014, p.111). Finally, creating an audit trail through the memoing process, and prioritizing researcher reflexivity within it, increased transparency and accountability in decisions made during the research process and in the analysis of the data (Lietz, Langer, & Furman, 2006).

## **Chapter 5: Study Findings**

### **5.1 Overview**

The focus of this research was on the ways that emerging adolescents with ADHD and their families experience ADHD in their lives and respond to it. Guided by the writings of Charmaz (2002; 2008; 2014) and others, the data was systematically gathered and analyzed using the CGT methodology. Through a structured CGT analysis, I became increasingly aware of how participants were telling stories about dynamic, evolving constellations of experiences of families of adolescents with ADHD. As analysis progressed, it appeared to me that this constellation of experiences represented a form of metaphorical journey that proceeded from experiences of challenge, and proceeded through stages of adjustment and growth, often including feedback loops. Through analysis, I interpreted categories and subcategories which comprised the families' metaphoric journeys. As interviews progressed, I asked new participants to reflect upon this metaphor, and various of the categories. Through our dialogue, among other things, categories were re-shaped and I discovered additional characteristics of the metaphorical journey, including that it was open-ended and ongoing.

The findings described below, therefore, represent the co-construction of the stories told by participants, as understood by the participants themselves and by myself, as the researcher. They seek to convey the participants' understandings and descriptions of the challenges that emerging adolescents with ADHD and their families face, and the ways that they respond to them in seeking positive outcomes for family members, and often, the broader ADHD community.

The first section provides a description of the participants. The second describes participants' understandings of the concept of resilience. The third section describes a core category: the process of families experiencing the challenges and struggles of ADHD, understanding them both as a biological and social reality, and responding to them.

Overall, the findings tell a story of families experiencing constant daily stress and often feeling that they are operating at the full capacity of their emotional, social and financial resources. Participants described how this often occurs within an environment that families perceive as inadequate in providing enough appropriate social, health, and educational support. Within this context, the families described by many of the participants were often initially shocked and felt overwhelmed by an ADHD diagnosis, yet gradually became open to accepting it, coming to understand it both as a biological and social reality. From this understanding, many of the families described in the data forged courageous responses - by integrating their resources and approach, by looking outward, and by seeking to work within and in some cases, challenge the social reality of their situation. The findings, thus, tell a story of families who came together as a unit, and sometimes with other families, working hard in seeking what they felt was a reasonable quality of life, yet often feeling that they needed to fight against unfair systems to do so. Nonetheless, through this process, participants described many positive outcomes, including families who felt they improved their understandings of themselves and society, forged supportive new relationships within their own family unit and with other peer families, and, in many cases, through struggle, experienced new meaning and purpose.

An interesting aspect of the data was that the adolescents interviewed presented a largely positive view of their experience, which may have been the result of how the interview questions and context were framed and the way in which interviews began with a discussion of resilience.

In addition, it is likely that family situations fostered strong support for them, potentially reflecting that the adolescent participants were from middle class families where parents had higher education and stable employment. At the same time, many participants described other adolescents with ADHD who felt frustrated and were not experiencing positive outcomes – for example, those who were experiencing conduct disorder or had become involved at a young age in alcohol and substance abuse. I was left wondering how the voices of these adolescents might be captured in future research.

## **5.2 Demographics**

Participants in this study were from three groups. 9 were caregivers (including 8 birth and adoptive parents and one grandparent), 3 were adolescents with ADHD, and 9 were supportive professionals (including 5 educators and 4 community workers or advocates). Participants were from three geographic areas in Canada: 3 were from the Edmonton area, 8 were from the Greater Toronto area and 9 were from the Ottawa area. Interviews were conducted in person and by telephone between January and July 2018. Of the supportive professionals, 7 were female and 2 were male.

For the caregiver and adolescent participants, 4 of the 9 families represented had offspring who were from minority ethnic groups and were adopted, while 5 families represented had children related through birth to their caregivers. All the families were of a middle-class socio-economic background, and the parents or caregivers were married. Eight of the nine caregivers had a university degree or other higher education. Of the caregivers, 2 were male and 7 were female. The adolescents ranged in age from 9-12 years and consisted of 1 male and 2 females. Each had been aware of their diagnosis for one year or longer. One adolescent

participant chose to take part in an interview with their parents, however, offered few comments. A summary of difference in the participants' characteristics is provided below.

Table 2  
*Demographic Information of Participants*

<u>Participant</u>	<u>Female</u>	<u>Male</u>	<u>Majority Racial/Ethnic Background</u>	<u>Minority Racial/Ethnic Background*</u>
Parent/Caregiver <i>(Adolescent related to parent/caregiver participant)</i>	2 (3)	7 (6)	9 (5)	0 (4)
Adolescent Participant	2	1	0	3
Professional	7	2	9	0
<i>Note.</i> There were 5 adoptive families and 4 birth families * Indigenous, Caribbean and African heritage				

### 5.3 Understandings of Resilience

At the beginning of the interview, the concept of resilience was introduced to participants to remind them about the goals of the research. At this time, I noted that there are different approaches to resilience, including those that are more limited and focus upon overcoming challenges, and those that are more expansive and include elements of positive development. Participants were asked if they were aware of the term resilience, how they understood it, and which approach, if at all, they felt was generally the most appropriate in the context of emerging adolescents with ADHD and their families. The ways in which the participants described and understood resilience are described below.

Key foci for adolescents when discussing the concept of resilience were day-to-day challenges of ADHD, and how an adolescent needed to be able to overcome them to proceed in a given day. For example, one adolescent described the challenge of not being able to accomplish a daily task or learn something at school as easily as others. For her, resilience was about having an attitude and approach of “I’ll try again and do it again, and (this time) get it right.” Another adolescent described the challenge of not being able to find something in the morning and felt that resilience was being able to accept that it would not be found and “make the best of it” to ensure that they, nonetheless, got to school on time. Similarly, several parents described their approach of facing day-to-day challenges as a constant, daily process of being able to “move forward.” For example, one mother, in describing what she felt resilience was, stated:

And so, the resilience is, can they deal with the stuff that's coming up and can they continue to move forward, even if it's two steps forward and one step back or three steps back?... (Can they) grow from the things that have happened instead of just getting stuck and sometimes they will get stuck because when you have ADHD it's harder to learn from things.

This appeared to the researcher to align with the definition of perseverance as “continued effort to do or achieve something despite difficulties, failure, or opposition” (Meriam Webster, 2018).

Several participants also noted that emerging adolescence was a time when social challenges were becoming more pronounced for many adolescents. Facing such challenges, one adolescent felt that resilience was being able to be flexible and see the potential for friendship with many people: “If a kid doesn’t want to be with me, I just say ‘wow’ and I’ll go find

someone else to play with.” Similarly, several parents felt that they had needed to support their child to accept different patterns of friendship – for example, less long-term friends and more intense, short-lived friendships than neurotypical peers experienced. For them, resilience was being able to find short term, daily solutions to social challenges that appeared for the adolescent.

Other participants felt more comfortable with a broader concept of resilience which implied, as one parent described, an adolescent “finding their own path,” and feeling a sense of success within it. For example, one parent described a resilient adolescent as one who could face challenges and continue to have their own dreams:

It's a kid that isn't destroyed by... challenges, isn't shaken by it. Because kids with ADHD have a lot of that anyway, but the kids that are resilient can weather it. Of course, they're not going to weather it alone, but they're going to weather it and still have hopes and dreams or passions for themselves.

In this regard, it was notable that more than half of the families referred to sports as a key area where their adolescent experienced personal development and success that they carried into their everyday lives and understandings of themselves.

The majority of parent/caregiver participants expressed some hesitancy with the term resilience. Several felt that it was misused to suggest that families should be functioning more effectively or with less challenge than they were, and in so doing, created negative, stressful connotations for them. For two parents, resilience was a term used by schools and programs to “scapegoat” individuals and families for problems that the adolescent was experiencing, rather than encouraging the institutions themselves to adequately support them. Four parents expressed

frustration with the idea that resilience could come naturally for adolescents with ADHD, and felt instead, that it had to be purposively and intentionally nurtured by families, schools and social programs.

#### **5.4 A Core Category: Families Journeying Together**

The central finding of this research was that not only adolescents, but also families who seek to support them, face significant challenges across multiple domains of life. These challenges result in struggles for families of adolescents with ADHD that are understood to be different in nature and quantity than those of families with neurotypical teens. Faced with a diagnosis of ADHD and its ongoing, dynamic effects that may have begun in childhood and then continue into early adolescence, families often initially had the experience of being surprised and disappointed by an ADHD diagnosis. From this, where able, many embarked upon a process of understanding – not only about the biological nature of ADHD and its impact on the adolescent and family, but also about the social circumstances of ADHD, including stigma and a lack of adequate educational, health and supportive services. Families often then fashioned a response to the circumstance of having an adolescent with ADHD in Canadian society - both by integrating their own resources and approaches, and by engaging actively with the world outside their family, including advocating for the resources that they felt they needed. The aim of this advocacy was to work through ADHD-related challenges of the adolescent, and to help all family members thrive.

A core category of *Families Journeying Together* represented these experiences and perspectives. The metaphor of *journey* referred to the long term, often uncertain nature of living with ADHD in a family, and the need to respond to its myriad challenges over time, including

both constant day-to-day challenges such as behavioral problems, and the broader challenges of finding ways for all family members to experience positive growth and thriving in their lives. The concept of *families* and *together* represented the participants' understandings that fragmentation should be avoided and that, rather, a higher level of family integration was required to respond to ADHD, including through the nurturing of attachment between an adolescent and parent even when increased stress on their relationship existed due to the emotionally dysregulating symptoms of ADHD. It also represented the participants' perspectives that families often seemed to feel alone as a unit, facing the challenges of ADHD without adequate support from educational, health and social systems, nor from peers. Notably, while participants identified personal characteristics that seemed to support resilience, including adolescent aptitudes such as high IQ or sporting ability, which is discussed below, they primarily situated the ability to face the challenges of ADHD at the level of the family.

The core category of Families Journeying Together is represented below with its three categories (Figure 1). The first category is *Experiencing Constant Challenge* and describes the various ways in which both adolescents with ADHD and their families relatively struggled compared to neurotypical peers across multiple domains of life. The second category is *Family Consciousness Building* and describes the “mind shift” of families from feeling overwhelmed by or seeking to avoid a diagnosis of ADHD to coming to accept it and seek out understanding regarding it. The third category is *Moving Forward* and describes a two-part process through which families assessed their own resources and sought to integrate and reinforce themselves as a unit, and became active in engaging with others, including seeking support and advocating for resources.

The three categories were present consecutively and suggested a basic process of responding to ADHD over time. However, data suggested that they do not develop in a linear manner in all cases, and rather represent an ongoing, dynamic process, through which families work on different areas at different times, and which they may cycle through regularly as they face the new challenges and/or different stages of development, such as emerging adolescence. The data also suggested that the different subcategories are mutually interactive – for example, that the understandings gained during family consciousness building are linked to the types of responses families make to ADHD, and vice versa. The discussion of the core category and its related themes and subthemes is corroborated below with examples and text quotes in support of the discovery of this grounded theory.

In addition to data supporting the core category of Families Journeying Together to fashion positive responses to ADHD, participants also described their own and their observations of others' experiences during which they believed a negative or incomplete response had occurred. Faced with the challenges of ADHD, participants described families who did not build their understandings of ADHD but rather avoided or minimized both the biological challenges of ADHD and the social challenges related to it. Instead of working collaboratively to enhance family integration and reinforce their own strengths, families became divided, often resulting in marital and family disharmony. Rather than looking outward and engaging with external organizations, instances were described of families who became isolated and sometimes felt embittered and alone. Although not always aware of the background circumstances of families in which this occurred, participants noted that some of these families appeared to lack adequate support and resources – for example, families who were unable to access quality health care, who lacked the support of their extended family or community, or who experienced barriers to

active engagement with supportive services, such as a parent’s mental health/illness. In this study, these became negative counterexamples of the processes of resilience-building.

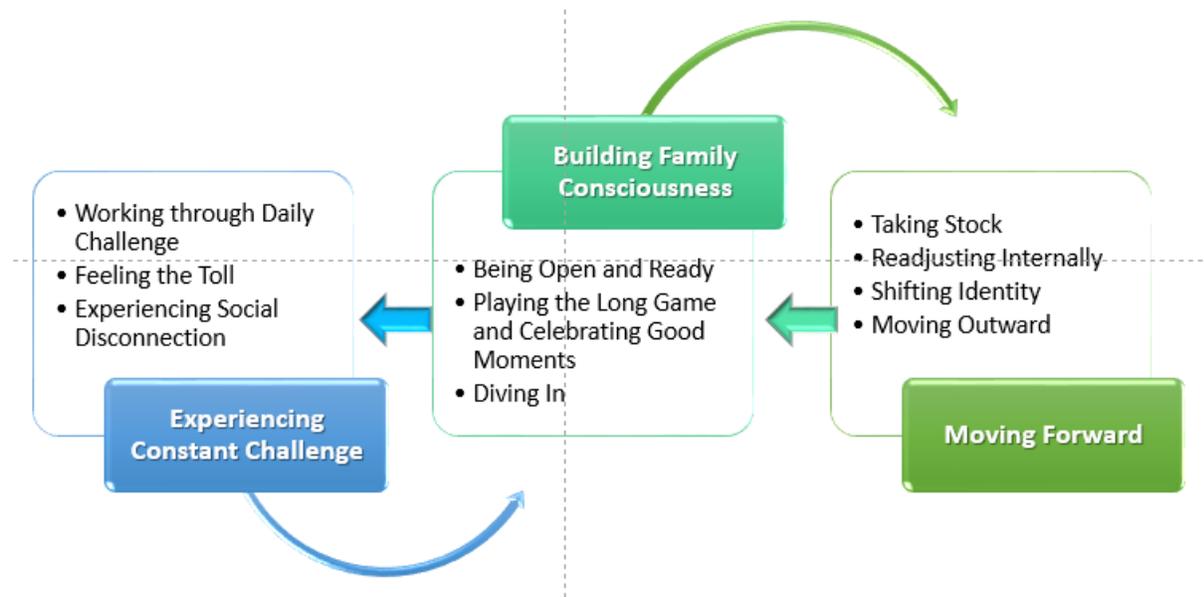


Figure 1. Families Journeying Together

#### 5.4.1 Experiencing Constant Challenge

Participants described a constant, pervasive set of challenges for both adolescents with ADHD and their families. The adult participants described how these challenges often began in early childhood and changed over time. They underlined how challenges changed in nature during emerging adolescence as adolescents sought more independence which they were not generally as ready for as neurotypical peers, and concurrently schools expected a higher level of independent functioning and social pressure increased. One parent described the “constant” nature of these challenges as follows:

The symptoms of ADHD... can cause social difficulties, learning difficulties, function difficulties, organization difficulties, and all those work to control areas of a child's life. And so, it means it can become harder to learn in school (and) there's the emotional regulation issue. It can cause challenges in families.... And then you... have the social aspects that are challenging. So, I think children with ADHD are constantly faced with challenges.

A key aspect of these challenges was that the adolescent with ADHD often was misunderstood by those outside and sometimes, inside, the family, given the limited visibility of ADHD symptoms. The three central experiences of challenge described by the participants are outlined below: *working through daily challenges* for adolescents, *feeling the toll* for parents/caregivers and *experiencing social disconnection* for families.

**Working through Daily Challenge.** Participants identified key areas of daily challenge for the adolescent, including being sufficiently motivated and organized to get to school in the morning, taking part in the school day without significant need for discipline, and following basic nighttime routines and schedule. However, they placed the greatest emphasis in their responses upon the inter-relational and social challenges of ADHD for emerging adolescents. First, they noted how neuro-developmental differences, including inability to perform many of the same tasks as their peers, led to negative impacts on self esteem, understandings of self, and ultimately the motivation to do well in school or to take part whole-heartedly in social or recreational activities. In describing adolescents with ADHD with whom she worked, a community advocate described that, by the time they reach the age of early adolescence,

They have experienced so much failure... (and) challenges with motivation, and just energy.... they tend to give up easier and sometimes they won't even engage in trying because... they go into it expecting to fail and I guess they have had so many failures that they don't want to try.

Several parent/caregiver and professional participants drew attention to increased social challenges, as the differences between emerging adolescents with ADHD and their neurotypical peers became more pronounced, and as general social pressure increased. As one community worker stated:

That is the age... it starts the patterns and it's so important they start learning how they're different from each other and they value themselves and that's why resilience is so important for them because they're going to try out different behaviours and they are going to fall down and make mistakes but they have to learn from them... it's also that time of the greatest social pressure. The world is happening right at that time... Right there in grades 6, 7 and 8, it's brutal.

Several parent participants underlined the challenge of some adolescents who craved significant social contact yet had difficulties maintaining relationships due to unpredictable, impulsive, and sometimes aggressive behavior, or due to atypical social mannerisms such as excessive or loud talking. Several parent and professional participants also noted that a challenge for some adolescents was their impulsivity on social media, where it was impossible to delete or “take back” what was said.

**Feeling the Toll.** Parent/caregiver and professional participants also described the challenges of families of adolescents with ADHD – described by one parent/caregiver as a “huge

toll.” A key concern was the high parenting workload; for example, the time that it took to provide heightened supervision and maintain structure in the adolescent’s day, as well as (or, in some cases, rather than) accomplishing other daily household tasks, such as preparing food and cleaning. Other participants described the financial effects on many families, such as the need to re-evaluate family finances and parental careers. Five out of nine parents/caregivers, the majority of whom were mothers, identified that they made career changes that involved working fewer hours or taking many years off paid employment. As one supportive professional described:

...the cost to families is high. So often families find they need to make a choice about what they can afford. So, you often find that ... mothers end up quitting their jobs because of the constant calls from the school ... to pick them up because educators and care providers just don't understand the condition.

One parent felt lucky her family had sufficient resources for their own needs, but wondered about the challenges of other families:

We were lucky that we could keep affording psychological services. But how many families cannot afford that. I wasn't working, there was no way I could work at that time, and childcare was not an option, so it was huge, a really hard time.

Similarly, three other parents expressed concern about families who lacked resources to access appropriate, timely services.

Another key concern was the emotional toll on families, and specifically that of parenting a child who could regularly become “out-of-control” and emotionally dysregulated. One parent described the experience of aggression by an adolescent with ADHD as follows:

When you're trying to be giving and understanding and your child is still being aggressive, you get to a point where you're not patient anymore. You feel, 'I've tried to work with you, but you're choosing me as an enemy'... They're destroying the room, then they're freaking out on their sibling who is getting scared. It's just horrible, it can be very horrible.... And... you could be having a great day with lots of energy, but when something like that happens, you're exhausted, you're upset, you just want to crawl under a rock and you can't wait to get the children to bed and then you cry about it or you go walk away and go to the bathroom.

Several parents offered jokes or humour during their interview about the emotional toll, and described humour as a way that they tried to cope with the stress created by an adolescent who experienced regular emotional outbursts. A notable challenge for several families was the development of marital conflict related to the demands of parenting, which several participants identified might be greater if co-parenting with a spouse who also had ADHD.

**Experiencing Social Disconnection.** Most adult participants described the wider social environment as creating challenges for families. They felt that there was a lack of understanding in society about ADHD and the fact that it was a “real” disorder, rather than the result of poor parenting or a moral and behavioral fault in the adolescent. Most parent/caregiver and some professional participants linked this lack of understanding to social stigma that families experienced daily, for example, when shopping or attending social or religious gatherings. One community worker described this stigma as follows:

Families often are really struggling. Some are totally isolated, and they turn inwards especially for those who have kid with behavior issues, because... (of) the amount

of judgement they experience... For example, in a grocery store, people feel that they have the right to comment on child behavior and on ADHD...comments that are stupid really. They say that the parents are lazy and try to put wrong labels on things. For example, they say...it's diet. But it's clear that if someone told them a kid had asthma, cerebral palsy or autism even, the family would get less of it. People think inappropriately and make inappropriate comments about a medical condition that they know nothing about. And unfortunately, the media doesn't help.

One parent described that her first reaction to this stigma (and she suspected of other parents), was to socially isolate herself. She felt that over time she had needed to fight this instinct to cut herself off from social relationships:

...they (other people) kind of look at you but I think that I have good confidence and self-esteem, or I think I'd want to crawl under a rock and never come out. I think a lot of moms end up isolated like that....

Other parent/caregiver and professional participants identified how, due to lack of understanding and embarrassment over adolescents' behavior, families had reduced their social contact with both friends and other family members, reporting that it was "just easier" to stay home.

A key site of challenge described by all participants was school. Most participants identified conflict between teachers and school administrators, and parents and adolescents regarding ADHD symptoms and their management in the educational setting. However, there were notable differences between the perspectives of most professionals, and particularly, those involved in the educational system, as compared with the parent/caregiver participants.

Several teachers noted that while ADHD was not considered an “exceptional” condition (under educational legislation) that led automatically to increased supports within the school system as compared to conditions such as ASD, some schools had adopted a flexible approach whereby students with ADHD received needed classroom and social supports. Several felt that the key site of challenge for families was not school, but home, where behavioral problems were more frequent and less controlled. These challenges were reportedly intensified when parents had been unwilling to accept the diagnosis of their adolescent, unwilling to use the supports provided to them or were overly-critical of school efforts to create appropriate accommodations for the adolescent. At the same time, one professional was critical of how the educational system was addressing ADHD:

I feel there has been such a huge influx of behavioral exceptionalities that the kids who have ADHD are not given nearly enough time and extra support that... they... need. Maybe they don't all need (this), but certainly some do.... because there's so much attention focused on putting out the fires for other kids, other needs that are causing harm... I think regrettably there a lot of kids who are falling through the cracks in terms of being as successful as they could be, because they're not given the time that you'd really like to help them navigate through in being successful and moving forward.

In comparison to the variety of opinion between supportive professionals, all the parents/caregivers expressed concern that their adolescent was currently, or had been, misunderstood and failed to receive appropriate accommodations. Several expressed deep frustrations and a sense of being “let down” by schools. Most parents/caregivers felt that many school personnel lack understanding about the extent of distress experienced by their child at

school, and were frustrated by the school's inability to support her/him to both learn and engage in social relations to their full potential. Several parent/caregiver participants were critical that ADHD was not an included "exceptionality" within educational legislation and felt that the result was that they had to "fight" for their child to receive services. Several also felt that the health system was often inadequate to address the needs of adolescents with ADHD, including not ensuring that front line medical professionals had "up to date" understandings of ADHD, nor ensuring that adolescents had timely medical care for acute challenges.

In addition, most parents described what one labelled a "disconnect," and another called a "misfit," between their adolescent's needs and available wider resources, including opportunity for families to share information and learn from each other. One parent was particularly surprised by the lack of centralized information for families, which she compared to what she had learned did exist for children with learning disabilities or ASD:

.... I think I'm still finding things out because there's no central place where you can get information. Even professionals for example - I just found out that... there are doctors that specialize in ADHD. The doctors aren't telling us this information and the schools aren't telling us. The fact is that it's not even considered a special condition. (This) is a huge barrier....

By way of summary, participants identified that both adolescents and their families were operating under a higher level of stress than neurotypical peers and families. Several noted that many adolescents with ADHD seemed to become, as one participant described, "sucked" into negative outcomes, such as alcohol and substance abuse. Most professional participants felt adolescents with ADHD were constantly at risk of adverse outcomes in their lives. Similarly,

most parents/caregivers portrayed in their interviews an underlying sense of unease as they described the current situation of their adolescent and looked to the future. They felt that, as compared with neurotypical adolescents, their families experienced not only greater daily uncertainty about what challenges would be faced, for example, due to behavioral concerns, but they also held significant worries for the future, including whether their child would be able to hold full time employment or would become involved in criminalized behavior or substance abuse.

#### **5.4.2 Building Family Consciousness**

In the face of these challenges, participants described how families sought understanding of ADHD not only as a biological reality within the adolescents' lives, but also a social reality for the entire family. A starting point for this process of seeking understanding commonly began with the families' surprise when they received the ADHD diagnosis. Generally adult participants described situations in which families had either sought medical assistance due to challenges with their child at home or were referred by schools for assessment of ADHD or a different developmental condition. After concluding the assessment process, most adult participants described how families commonly felt unprepared to receive an ADHD diagnosis. As one parent participant described, it was like being caught as a "deer in headlights," "frozen in place," and being "off balance" when they found out their child had ADHD.

Only two parents/caregivers felt that they had taken the diagnosis "in stride" and were relieved to receive it. For the remainder, some appeared to deny or seek to avoid the diagnosis, while others felt overwhelmed by it, wondering and worrying about what it meant for their child and family's future. As described by one parent: "...after we got a diagnosis, finding support was

very hard...(A)ll the clinical material was very depressing so there were a lot of tears and heartache..." Several of the parent/caregiver participants remembered their first reactions upon hearing the ADHD diagnosis was to think back to what they had heard about ADHD in the news/media, including that it was over-diagnosed, led to overly-prescribed medication, and was the result of lazy or incompetent parenting. They further identified feeling confused about whether they should accept the advice of medical professionals to try medication for their child.

From this place of surprise and confusion, most parent and professional participants described a process by which families came to recognize their need to expand not only their understanding of ADHD as a biological reality, but also ways it is approached in society. From this, came an exploration of ADHD and its impacts in the short and longer term for both their child and family. This was a process not only of education, but of consciousness-building – including elements of both learning about ADHD, and the social stigma and isolation related to it in society. The following three components of consciousness-building are described in more detail below: *being open and reading, playing the long game while celebrating good moments* and *diving in*.

**Being Open and Ready.** To develop this consciousness, many parent and professional participants described how families needed to move beyond feeling like a “deer in headlights” and become ready and open to the diagnosis. One parent described this as a process of having a “mind shift” as follows:

.. I think that when parents realize the hand that they've been dealt, and see it for what it truly is, and they see it's not just a deficit.... that's a huge mind shift. Our

kids need to know that we have their back and we believe in them and we're going to always be there.

Similarly, several supportive professionals described situations in which a lack of family openness and readiness created barriers to resilience, particularly in working productively with the school. One teacher remembered the family of an adolescent who was now experiencing addiction as follows:

He had a family that was very tight and tied in with the community, and I guess for whatever reason they didn't want to recognize...his regulation issues and it didn't help them with it... We know that when they don't get help with that regulation issue when they're (younger) and when they get to high school, well, they're just going to get pulled into drugs....

Several professional participants reflected upon families they had known and wondered if some parents had been unable to fulsomely accept a diagnosis of ADHD for their adolescent due to surprise, fear and anger at the diagnosis, and emotional or cognitive challenges that created barriers to adjusting their mindset and home life to accommodate their child's symptoms. Several professional participants identified particularly challenging situations in which a parent appeared to have undiagnosed ADHD or were experiencing depression or anxiety that appeared to be triggered by their child's ADHD symptoms.

**Playing the Long Game and Celebrating Good Moments.** Most parent and professional participants felt that an ADHD diagnosis was only one step in understanding the impact of ADHD on the adolescent and the family's life, and it was additionally important for them to accept its potentially life-long impact. Families who were able to fashion positive responses to

ADHD came to accept that there was no “magic bullet” solution for ADHD symptoms, such as medication or short-term counselling that could “correct” the diagnosis, and that instead the family itself would need to undergo often-difficult change. As stated by a community worker:

The one problem is that even with knowledge of how ADHD impacts their lives, and what strategies can help, there is no magic bullet and sometimes parents think they will find that and a way to make ADHD go away. The.... main message... is that this is hard work. I have lots of people call and ask if there is a course they can send their child to and I ask what it is you want the program to do. And they say they want to take ADHD out of their child. I say there is no program that can do this, but I do have a program for you. This is hard for lots of parents to realize that they need to change. They can help make things better in their home, but it is a difficult life.

When families were able to accept this need for family-level change, many professional and parent/caregiver participants described how they were able to adopt a mindset of seeking long term positive outcomes, within and not apart from the experience of ADHD symptoms. A teacher described this as a time when families were able to accept the disabling aspects of ADHD, but also to see the long-term potential in their adolescent:

... I think for the parents, one thing... is recogniz(ing) that yes, they have a child with this, and... their child can accomplish great things if they can give them the right support to do so ..... It's something that, you can see it as an exceptionality, but also it can be seen as a gift too, and I mean in life different people excel at different things, because they are all different. So, it's ... set(ing) up the right things

for the people who have it. And then they can go on to do great things... win-win for everybody...

For the teacher, it was notable that some families appeared able to do this, while others were not. Although she did not have a detailed understanding of family background that contributed to the difference, she noted an example of a parent who appeared excessively negative about her adolescent's potential. This parent had appeared to the teacher to feel overwhelmed and socially embarrassed by the adolescent with ADHD, frequently publicly contrasting him/her to a sibling who was neurotypical.

Several participants also noted the interaction between how parents/caregivers and adolescents came to understand and reflect on ADHD as an aspect of their family's life. As one parent described:

.... as long as we (are) feeling we are working together, that makes us resilient. And, as long as he doesn't put up barriers, that's good. But, if he were the kind of kid that said I can't organize and I'm going to give up, to me that wouldn't be resilient. He's good to say that's difficult me for me... (It's) an attitude... us, as parents, having been so careful with how we work with.... challenges and how we message him because I think we could've done it in so many other ways where we ended up with a child that says, I'm not even going to try, what's the point? We work so hard....

Comments such as those above underlined the interrelationship between parents and adolescents in terms of how they understood ADHD and how they approached resilience as a collective act.

Several parents identified that a key shift in outlook was to view the future as what one parent described to be an “open book” while deliberately focusing upon small successes in their adolescent’s daily life. One parent, for example, described the need to celebrate small victories in her adolescent’s sports activities as well as moments of calm in her home as follows:

(It’s about) really being honest and celebrating the win. And wins are the good moments, the happy moments. For me it was really just slowing things down and not always being in a state of turmoil. .... I think as a family unit finding things that you enjoy doing together and doing those things so you’re not just constantly thinking about bad things you don’t like.

This process of being open to the future while focusing upon “good moments” was perceived to be essential to building resilience. It was felt by a parent that this process “reenergizes you, rebuilds the state of the family unit and helps keep going.”

**Diving In.** A final aspect of family consciousness-building was extensive study by parents to increase their understanding of ADHD. Several of the parents described a process of what one termed “going deeper and diving in” to resources, including print and online material that would help them not only understand the diagnosis but also provide practical strategies on how to manage daily life.

However, this process of *diving in* did not stop with understanding ADHD, but also extended to how it was responded to and treated by society at large. It included identifying what one parent described as the “tired embarrassment” that parents/caregivers and adolescents often felt regarding the adolescents’ behavior. It also included becoming able to understand this embarrassment as a feeling that resulted from social stigma rather than an inherent fault in the

adolescent or family. Several families felt that this shift in perspective had been supported when they sought advice, and received peer mentoring and informal counselling within a church or community setting.

Several parents described how they accessed online materials, joined online support groups or had personal experiences that helped them to gain a better understanding of the United States-based educational and social supports for adolescents with ADHD. From this, they described gaining more understanding about ADHD as a disability that required support, and identifying how limitations of support in Canadian schools and society were a cause of their family's struggles.

Notably, this process of *diving in* was described by most of the parents/caregivers differently than by professional participants. Professional participants generally emphasized the importance and way that families informed themselves about the biology of ADHD and how as several professionals described, they, as parents, could best support the adolescent, for example, through structure and positive reinforcement for good behaviors in the home. In contrast, most parents/caregivers felt that it was important to move beyond this and come to understand themselves and their child as impacted by how society responded to ADHD. This was apparent in the frequent references that parent/caregiver participants made to their direct personal experiences of feeling embarrassed by their adolescent's ADHD-related behaviors and diagnosis, and to a general experience of feeling stigmatised by how ADHD was understood and referred to in society, for example, on the news. They commonly described how they often had begun their journey with ADHD by passively accepting feelings of embarrassment and personal fault, yet gradually, by reading about other families' experiences and, in several cases, learning about how ADHD is understood in many areas of the United States, came to understand their experience as

being reflective of social misunderstandings about ADHD in Canada. Similarly, one of the adolescents described how s/he had at first felt “bad” when s/he didn’t understand something a teacher or camp counsellor was explaining, but had come to understand that she was different than many other adolescents and that while these adults in positions of authority were “smart”, they didn’t always understand how s/he and “other kids” like her were best able to understand and learn.

### **5.4.3 Moving Forward.**

Occurring as a result of and along side consciousness-building, participants described a process of the family moving forward to respond both internally and externally to support its members. In comparison to consciousness-building, which was generally a more passive step of learning and reflecting, moving forward represented the families’ active responses to what they had learned and come to accept. Below three processes of moving forward are described: *taking stock*, *readjusting internally*, and *opening outward*.

**Taking stock.** Many participants described how families undertook a step of practically “taking stock” of the family’s resources relative to the adolescent’s needs. Several professional and most parent/caregiver participants identified a need after diagnosis for families to be able to understand an adolescent’s strengths and potential, as well as their challenges and difficulties. As one supportive professional described, families had to put together the “puzzle pieces” of their adolescent. This included identifying the “type” of ADHD and any comorbidities such as learning disabilities or mental health challenges, and the adolescent’s greatest experiences of challenge, for example, at school or in unstructured environments with friends. It also required identifying and articulating to themselves, their child and their family, their adolescent’s

strengths. For example, several families identified an adolescent's interest, even if not about achievement in sports, as helping them to experience some success and a way to think about the world. Several professional participants also underlined how strong intelligence helped to support adolescents with ADHD in coping with their behavioral and cognitive challenges. Taking stock involved moving beyond what one participant described as a "cookie cutter" approach to examine the reality of the adolescent's situation, strengths and needs.

One aspect of taking stock for the adolescent included evaluating the family's approach to ADHD medication. Several of the parent/caregiver participants described how they had initially been opposed to medication. However, the majority had come to accept it as a necessary support to allow their child's best potential to be achieved, and to improve their ability as a family to respond to the challenges of ADHD. As one parent described:

Let's be clear - medication changed everything. It heightened the executive function, so we could see (our child's) potential and heal (their) self-confidence. The reality of (their life) became to approach closer to (their) potential. So, instead of... a vicious cycle (of failure), suddenly working hard led to success (for our child) and over time, it became intrinsic motivation... Failure didn't become catastrophic... (We could) get past the first response of "no" (to new things) .... It was night and day at school in terms of the progress... We also noticed it in the social dimensions, navigating relationships, slowing down to think through the steps, considering options and making a good choice....

Despite concerns about any long term and side effects of medication, most participants felt that medication, though not a panacea, was essential for most adolescents to be able to identify and draw upon their personal assets.

At the family level, various processes of taking stock occurred. A key concern was to assess whether the family had, in its present structures and routines, the financial and personnel resources to support the adolescent. A key consideration was how families could handle the increased daily caregiving needs for their adolescent, including frequent medical appointments and school meetings to address their child's behavioral challenges, increased caregiving needs due to expulsion from school or the adolescent being unable to attend after-school programming, as well as increased daily needs for support and supervision, which reportedly contributed to parents experiencing "burnout." Taking stock included evaluating whether both parents could continue to work, or whether one, generally the mother, would either quit or decrease full time employment, or the family would reallocate resources to hire additional care for their child/adolescent. It also included identifying how grandparents and extended family were or could become a source of potential increased support and had come to play a key positive role in the lives of adolescents with ADHD by helping to support them and provide respite to their parents/caregivers.

Participants described a process of *taking stock* of wider community resources and ways in which they might be accessed. This included identifying barriers to accessing resources that would be used by neurotypical families. For example, two parent/caregivers identified how their adolescent's behavioral challenges led to frequent friction and alienation from others, leading to the need to change their recreational activities regularly. Another parent identified how his/her own shyness and desire to "fit in" had been a barrier to taking part in church activities even when

he felt uncomfortable regarding his child's behaviors, leading him to re-evaluate how he approached social settings. Several participants also described how they needed to regularly take stock of their own emotional resources, including burnout and experiences of anxiety and depression that they related to their experience of parenting an adolescent with ADHD.

It was notable that several parents described feeling disappointed by community resources to support families of adolescents with ADHD. One area of concern was that existing organizations were often not specialized in ADHD and offered inappropriate support, for example, focusing on social skills development. Two parents also identified challenges with family counselling they had received, as it failed to address day-to-day life and the specific parenting challenges associated with ADHD.

**Readjusting internally.** A second aspect of moving forward involved internal readjustments to the family's daily life routines and structures. Participants described how readjustments occurred at diagnosis but were also necessary at regular intervals as life events occurred such as the adolescent changing to middle school or families moving. A focus of these internal adjustments was to ensure that the adolescent received the extra support they needed for daily tasks and that families were able to function with appropriate levels of structure that counteracted what one parent described as the "turmoil" ADHD could create in daily life.

For parents, an important step in family adjustment to ADHD was accepting a "new normal." As described by one parent, "It's about letting go of expectations of yourself, life and your children, and letting yourself be open-hearted and open-minded and expecting a new normal." Often this required building a sufficient level of flexibility in daily life to handle the unexpected needs that ADHD might present. As another parent described:

as a parent, you have to be willing to alter your plans and I think that's a resilience factor. I think we are... lucky that we have jobs (and) were able to work opposite schedules. And we're lucky one of us can always be there and that means we have the option of doing things a lot of other families can't... We can deal with things immediately as they come up....

The parent attributed the family's flexibility both to mindset and having two parents with stable careers and a supportive extended family. This parent worried about others who did not have this ability as follows:

If (I was) a single parent, I don't know what my child would do.... we have jobs where we can organize.... and respond to the things that develop. If you don't have the time to do that, I think the challenges would amplify.

An additional adjustment was the need for adolescents to become increasingly self-aware of their diagnosis and the ways it impacted home and school life. One adolescent, for example, described how she and her parents learned to adjust their approach to learning – accepting that there was more than “one way” regardless of how a subject was being taught at school.

**Shifting identity.** Often a key aspect of this practical adjustment was an identity shift for the adolescent, parents and family. This shift for each role is described below.

*Adolescents.* Most participants identified emerging adolescence as a time of significant change in how adolescents thought about themselves, and a time during which they became increasingly aware of their ADHD diagnosis and how it affected their lives. Identity shifts were

noted as needed to support the adolescent in both accepting their disability and their potential for a happy, productive life. As one parent described of the identity shift her son undertook:

.... it's fostering confidence and self-esteem, and focussing on the abilities as opposed to a society that surrounds them that is focussed on looking at the defects or always calling it a disorder. My son only actually discovered - like he knew the term ADHD, but he... read what it stands for two weeks ago and he said 'What? you're calling it a disorder...are you saying there something wrong with me?' Just the word (disorder) suddenly... So, we had to have that discussion again... because he could've walked away thinking, 'Oh, now I'm considered a disorder.'

In nurturing positive identity formation, several parents reported the need for the adolescent to continue, through their challenges, to feel loved and accepted. As one parent stated:

And so, I think for parents it's everything. It's the community you choose to live in, the school they go to, the messages you give, sibling relationships and how they message each other and family- immediate and extended. The more the kid knows they're loved and supported, the better they'll do.

One adolescent identified that he was particularly helped by a parent who was able to introduce him to positive role models with ADHD to whom he could relate and aspire to be. Four of the parent participants also identified the need to help emerging adolescents begin to think early about their goals for the future.

*Parent/Caregiver.* Parents reported a need to undertake identity reformation. A key step was described as understanding that parenting style affects the expression of symptoms in

ADHD. As one parent described: “I think we realised that we can be part of the problem and as parents we were adding to the problem.” Most importantly, the parent participants identified their need to accept the increased demands of parenting an adolescent with ADHD, and the requirement that they become “more attun(ed)” to his/her needs in order to better anticipate and respond to them.

Several parents described becoming what one parent labelled, an “overboard” parent. As one mother described:

I (became) an overbearing mom.... but you have to be very involved to stay on top of things for your child. I had to follow my gut and I tell (other) parents, you have to as well...I am a stubborn parent and I was determined not to let my kid fall through the cracks.

Another parent described how being an “overboard” parent was different than the commonly used term “helicopter parent”:

I think it's very different than helicopter parenting because our kids have needs that are very different. Like I have to unpack his bag and I have to organize him because he can't do it. It's just not going to happen. So I find helicopter parenting is more when you're controlling, where as we work hard to not be controlling.... we're not just always imposing things. It starts with a dialogue and he's part of the discussion... that's the respect and he feels I care how he feels....

This included ensuring their child knew they were in “their corner.” As one parent stated:

(My son) had to learn that I'm in his corner no matter what. I'm going to fight for him no matter what. I know, no matter what comes up.... I can't control what the others are going to do but I'm going to advocate for him because he can't do that all himself....

Several parents identified that it was helpful to find meaning and purpose in their role as the parent of an adolescent with a disability. As one stated regarding her increased workload:

(Now), I just see that as part of being a mother. It's the most important job I have because my children... deserve the best that I can give them... I want them to be able to look back and to feel I did 100%... That's what drives me....

Similarly, another parent described a process of self-searching when faced with day-to-day demands, as follows: "I think what kind of parent would I be if I didn't do that.... I ask what if I take the easy way out what kind of parent am I?"

Additionally, several participants described the need for parents, like adolescents, to adopt a mindset of "rolling with the punches" in which they became able to accept the challenges of parenting an adolescent with ADHD in a balanced manner and in which they did not excessively compare their child to neurotypical peers or siblings. Several teachers and parents identified that a key factor in promoting resilience seemed to be the development of a flexible mindset among parents, in which parenting identity focused upon long term goals rather than day-to-day challenges.

*Siblings.* Identity shifting for the family also involved accepting the need to constantly undertake a complex balancing of the needs of all family members. One parent described a feeling of fear and uncertainty associated with what she called “this daily balancing act”:

Some of it is scary... and as a parent, you wonder if you should be putting the brakes on at some point. Are you enabling too much of something? ... (W)hat is a good balance? There is a need for family time, rest time and nourishment time for everyone....

The parent expressed the “struggle” of trying to continue to “make things fair when it is not all the same” between siblings.

Concurrent with families’ development of strategies for balancing members’ needs, was the process of shifting identity that occurred for siblings, particularly those who did not have ADHD. Some parents/caregivers described these siblings copying disruptive behaviors while others seemed to become overly cautious, for example, seeking to avoid what they perceived to be a mistake made by the other child. Participants identified the need to help younger siblings to understand ADHD in an age-appropriate manner. Describing how to support the relationship between an older adolescent with ADHD and a younger neurotypical sibling, a parent stated:

There's a dance and between them. It's difficult and very complex, like you're having to constantly manage that.... managing each of them and ensuring the relationship between them is still healthy. The one that has (ADHD) needs... more of your attention and that gets challenging too... (the other sibling feels) forgotten....

For older siblings, several parent participants identified the need for families to help them to reflect on the impact of ADHD on their lives. They felt it was important that siblings be encouraged to have their own adolescent experience, including making mistakes.

**Moving outward.** A final aspect of moving forward was reported as becoming outward-looking and taking action with partners and entities outside the family with the aim of meeting the family's needs. Despite the pull of becoming isolated to avoid experiencing stigma, an important step identified by a significant number of professional and parent participants was for families to build partnerships. A key partnership was with the adolescent's school. As described by one supportive professional: "when parents are wanting to work with the school and the administration, they form a bit of a partnership ... that's a real protective factor for the kids."

Beyond educational and medical institutions, many of the parent and professional participants identified a need for families to build partnerships with one another. Peer-based connection with other families was described to result in a better understanding of each other's experiences. For example, one parent noted that she would only feel comfortable sharing the deepest challenges of ADHD with parents of a child or adolescent with ADHD:

...when your child is having tantrums and times when (they are) aggressive, I remember saying to ... I understand why people might want to beat their child. Because I don't, and I wouldn't, but it sounds so horrible when you say it. But when you're in the situation of these extremes, (it's helpful when) you find people you can say that to.

Another parent stated that spending time with other families in which an adolescent had ADHD or other special needs "normalized" their experience:

When you don't have a child with ADHD, you have no idea what it's like, how it affects every aspect of your life, and some parents have easy children and you know, when you're around those families and your child does something, they don't understand. But when you're around families with special needs, you know there's no judgement. There's understanding and empathy...there's no judgement of the children and the children are still seen as wonderful kids. There's no one saying these are bad kids. But if you have people without that...they don't understand.

Notably, the lack of existing organizations in which families with children or adolescents with ADHD might come into contact with each other, was noted by several professionals. While two felt that adequate community supports existed but were not used by families, others believed that professional support for families of adolescents with ADHD was inadequate to meet their needs, and that peer connection might provide social support and opportunities to discuss helpful strategies for daily life. Although they described significant challenges in doing so, some of the parent/caregiver participants positively recounted their own efforts and the efforts of peers to build formal and informal partnerships among other families of children and adolescents with ADHD.

Moving outward also involved families becoming willing to, as one parent described, “take a stand” for their child against institutions they felt were not meeting his/her needs and discourses they felt were oppressive. For most parents, this involved individual advocacy efforts within educational and medical systems – for example, repeatedly reaching out to teachers and principals to ensure that their child’s needs and personality were understood as fulsomely as possible. Three parents noted specific advocacy efforts to ensure a school did not take away recess as a form of discipline, and one father noted that his family used a “voluntary suspension”

approach whereby they would take their adolescent out of school for several days if their behavior was becoming increasingly difficult. He described how this would “reset” the adolescent’s “clock” and ensure that she/he did not receive a mandatory suspension that would remain on her/his school record.

Several professionals reflected upon the families which were perceived to be “close” such that parents reportedly had been “difficult” and/or were unwilling to accept a diagnosis of ADHD. Although these parents were initially vocal in resisting the diagnosis, several professionals noted that their connection with and desire to support their adolescent had often led them to become, once they accepted the diagnosis, active and positive advocates for their adolescent.

Moving outward for parent/caregiver participants also included times when parents or caregivers advocated for the needs of the ADHD community more broadly, and particularly families that might be experiencing even greater challenges than a participant parent/caregiver. For example, several identified the challenges that existed for single parents, those affected by mental illness or ADHD themselves, and those living in poverty. One parent described helping a family member in her struggles with her child’s ADHD, and the subsequent questions it had raised for her:

I said to the school what are you going to do about it? You guys are making it worse.... How many other families go through this? So, I think.... it's great to say parents are going to go to the “ends of the world”, but some of them can't. They have their own issues and so who's going to help those guys and unfortunately the way the system is unless you push and push and push.... it shouldn't be that way. I

wonder about how it is for (other families) .... I see it as a multi-level system failure and it's huge.

For several parents, an “outward” focus led them to consider ways families affected by ADHD could be better supported in society, including through more funding for family support groups, better social education campaigns about ADHD, ADHD education for professionals like police, and effective respite programs. Many parents reported that they had joined or were in the process of joining associations that advocated for the needs of children/adolescents with ADHD.

Parent/caregiver participants identified the challenge of this outward focus, given social stigma and their own limited resources. Nonetheless, there was a reported need to, as one parent described below, “push through,” or as different parents described “not give up,” or “keep moving forward.” These notions were identified as a key mindset which helped families to resist social isolation and to embrace an outward looking, community and change-oriented approach.

As one parent described:

I think it's so important to push through all the challenges. I am influenced by what's in it for me and my family. The notion that this is a development disorder and beyond surviving, I want to push forward thinking I want to know what lies beneath us and how I can make things better....

At the same time, several parents/caregivers underlined their concern for other families they had met who appeared to lack personal and financial resources to advocate for their adolescent, noting that these adolescents seemed to, as one parent described, “get lost” in school and social settings.

#### **5.4.4 Summary of Findings**

The central finding of this study was the complex process of building resilience among many of the participating families and others known to the professional participants. This process was one of struggle and response: an experience of constant, diverse, daily challenge that families responded to by: (1) building a deep level of family understanding regarding ADHD and the way it is experienced in society, and (2) taking responsive steps towards positive outcomes.

## **Chapter 6: Discussion, Limitations and Recommendations**

This study of resilience in ADHD appears to offer promise in addressing some of the limits of research to date (Climie & Mastoras, 2015). This includes addressing a deficit focus, broadening what has been primarily a medical and educational research agenda to include the perspectives of other professions (e.g. social work), and helping to build understanding about supports and ways for individuals with ADHD to thrive. Further resilience research may improve understanding about how challenges associated with ADHD can be moderated, and how people with ADHD can be better supported across the multiple domains of their day and life-span.

This study contributes to this small but emerging body of research in four ways. First, to the existing literature that largely addresses early childhood and later teenage years, this study addresses an understudied area: the perspective of emerging adolescence. This includes both addressing unique challenges faced during this time of life and exploring the types of supports and experiences that appear best suited to nurture resilience during this juncture. Second, this study affirms the central role of the family in supporting resilience in emerging adolescence, and outlines pathways to building resilience that families undertake and in which they may be supported. Third, this study contributes to knowledge regarding the ways that policies, programs, and social conditions impact adolescents with ADHD and their families, and how some families respond. Finally, this study contributes a constructivist, qualitative research perspective from within the field of social work. This includes integrating the voice and direct perspectives of a select group of adolescents, parents and caregivers regarding the challenges to and opportunities for building resilience.

## 6.1 Resilience of Early Adolescents with ADHD

A key insight from studies on resilience is that there is no “one-size-fits-all” approach but rather that resilience is, in the words of Ungar (2004, p. 32) “complex... and contextual.” Put alternatively, there is a “plurality” of resilient expressions (Roberto & Moleiro, 2016, p. 931). The findings of this study affirm this insight for emerging adolescents with ADHD. The findings amplify emerging adolescents’ experience and needs as contextual and, in many cases, distinct, as compared with individuals with ADHD in other age categories, individuals with other disabilities, and neurotypical peers.

The findings of this study show emerging adolescence as a time of unique, cross-cutting challenges to resilience for those with ADHD. These challenges include becoming increasingly aware of one’s societal position as a person with a disability or “disorder,” while at the same time being at increased risk of developing comorbidities like anxiety, depression, oppositional defiant disorder or conduct disorder. An additional challenge is the apparent “misfit” of having a neurobiological profile which often seeks the stimulation of social contact, yet, at the same time, experiencing challenges in social abilities, for example, due to impulsiveness and inattention. A key cross-cutting struggle is the pervasiveness of ADHD symptomology (including at home, school, and in recreational and social activities), yet its largely invisible nature and the common and erroneous social attribution to a character flaw in the adolescent and/or their family.

Second, this study’s findings suggest that unique understandings of resilience, and specifically a concept that is broader than overcoming adversity, may be needed to face ADHD-related challenges. This concept takes into account the pervasive challenges of ADHD, social stigma and the developmental task in emerging adolescence of forming a positive self-identity.

Beyond overcoming specific adversities, resilience was demonstrated to include the process of sustaining positive development in the face of pervasive, permanent, immutable challenge. For example, instead of accomplishing the typical adolescent task of learning to “fit in” with peers, many participants described the need for adolescents to find alternative pathways to educational and social success that incorporated and accepted the adolescent’s *neuro-difference* and enabled them to work with and through it towards a positive future. Similarly, resilience for participants involved both perseverance to accomplish daily tasks that were considered difficult with ADHD, but also to experience the ability to maintain a positive sense of self and their longer-term “dreams.”

A key factor in this broadened concept of resilience was the family, with whom adolescents in this study articulated a strong sense of connection, and which appeared to play a central role in providing structure, social contact, identity support and affirmation. Notably, at a time of life when the neurotypical adolescent might be increasingly influenced by peers, the emerging adolescents in the study strongly affirmed parents as supporters and role models, who often connected adolescents with other role models, and helped them develop self-identity, positively experience social and recreational activities, and form plans for their futures. Resilience for an emerging adolescent in this study was, therefore, equally about accomplishing developmental tasks in an independent manner, and recognizing the need for and using assistance due to personal limitations.

An implication of the current study is that what resilience is and how it is experienced by emerging adolescents with ADHD, may not fit neatly into general models of resilience for early or older adolescence. As such, this study may suggest an alternative viewpoint to conclusions such as that of Boden, Sanders, Munford, and Liebenberg (2018) who suggested that general

models of resilience are applicable to vulnerable adolescents. Instead, the findings of this study appear to affirm Ungar (2004, 2008, 2015) and Roberto and Moleiro's (2016) emphasis upon the unique experience of resilience. It suggests a need for models of resilience which can account for the distinct, broad challenges in emerging adolescents of invisible cognitive and behavioral disabilities like ADHD. A model such as that of Kia-Keating, Dowdy, Morgan, and Noam (2011), which integrates Positive Youth Development with overcoming adversity, may be appropriate; hence, further research in this area would be helpful.

## 6.2 Family Resilience

In her book, *Ordinary Magic* (2014), Ann Masten outlined a “short list” of resilience factors that appear to support children facing various adversities including war and abuse. The list begins with “effective caregiving and parenting quality” and Masten concluded, taking into account a broad range of resilience factors, that, “an effective parent or someone in this role has proven to be the most important and pervasive influence on resilience in children” (p.153). Masten identified two primary roles of the parent and more broadly, the family system, in building this resilience for children and adolescents: (a) reducing the “exposure to and mitigate(ing) or buffer(ing) adversity”; and, (b) “through their influences on the development of adaptive capacity in the course of child rearing,” including cognitive development, problem solving and motivation, and cultural transmission (Masten, 2014, p. 212).

Masten (2014) identified various interventions aimed at supporting families in crisis, including home visits in at-risk cases, family therapy, and specific supports for crises-like bereavement and divorce. Notably, she did not identify the processes by which families build their own resilience either in times of crisis nor within the everyday experience of adolescent

disability such as ADHD. Similarly, the emerging literature on resilience in ADHD, such as the systematic review of Dvorsky and Langberg (2016), identified factors like positive parenting and family cohesion as resilience-building. While existing research has resulted in a call for further study of how these and other family-related factors are protective for adolescents with ADHD, the literature remains silent regarding how resilience building, in practice, takes place. One exception is Mitchell and Climie (2018) whose findings affirm the need for more effective family-based supports and which highlight the need for further study of family relationships in ADHD, including regarding the role of siblings.

This study contributes to literature like that of Dvorsky and Langberg (2016), Masten (2014), and Mitchell and Climie (2018) by adding knowledge to the aforementioned gaps and needs. First, this current study adds to understandings of how families build resilience in the lives of emerging adolescents with ADHD - identifying the family as mutual companions on a long journey whereby impacts are felt in a myriad of ways in each other's lives, including how they think about and frame their understandings of themselves and their broader social world. This includes defending themselves against stigma and against social and structural limitations created by an able-bodied environment that is largely uninformed about ADHD. This finding aligns with Masten's (2014) call to explore resilience from a family system approach and with recent empirical research that examines in greater detail how family systems operate to support adolescents with ADHD. As an example of such exploration, Ray, Evans, and Langberg (2017) found that social impairment was reduced not simply when adolescents were involved in sports but when their parents were also involved in helping them navigate the social world around sports. Research is needed to further explore how families affected by ADHD operate as systems, including the nature and types of parental involvement in different domains of life that

best support resilience in emerging adolescents, and the ways that family systems may be supported in being able to carry out these functions – even within the experience of parental stress and burnout. Following Mitchell and Climie (2018), further research is also needed regarding how siblings contribute to and affect family dynamics, particularly given that they may ultimately be involved in later life support for individuals with ADHD.

Another contribution of this study is to increase understanding of how families build their own resilience to support their adolescent with ADHD, where adequate resources allow them to do so. Rather than resilience being based upon innate characteristics or depending upon the direction of an institution or supportive professional, the current study's findings suggest that families with adequate resources, in the face of adversity including social stigma, can and often do undertake processes of building resilience from within, including parental determination not to let their child “fall through the cracks.” The basic process appears to be one of experiencing struggle, seeking to understand it deeply and responding through a process of integration of family perspectives and actions. This has emerged in these findings as a creative process in which additional resources, where available, are brought to bear on a problem – for example, where grandparents are brought in to provide respite care, and where parents reorganize their financial affairs or career to prioritize their child's needs. A foundation of this process appears to lie in strong emotional attachments within the family, supported by the persistent work of parents, even when parental stress is high, and attachment may be strained by ADHD symptoms like inattention, repetitive angry outbursts, and aggression towards others. Notably, as is discussed below, this study affirmed that the family's ability to respond creatively and effectively appears to be influenced by its material resources, for example, to reduce the career trajectory or salary of one parent to provide additional care for the adolescent with ADHD.

A key aspect of this process appears to be building family consciousness related to ADHD, which involves more than simply hearing and understanding the diagnosis through a medical lens. Rather, it extends to exploring how the diagnosis may impact family members' current and future lives, how families with children and adolescents with ADHD find themselves embedded in and impacted by an often oppressive, restrictive social reality, and how practical adjustments, identity shifting and advocacy may promote quality of life for family members.

In this sense, the resilience-building process for the participants in this study appeared to align, at least in part, with Freire's (2007) theory of conscientization that is influential in anti-oppressive social work. For Freire, the experience of social oppression called for (a) *problematization*, namely engagement in dialogue to probe and query reality, and (b) *conscientization*, the subsequent process of reflecting critically upon reality and acting towards its transformation. In this study, resilient families appeared to undertake, in a modified form, these steps – first, undertaking a critical identification and reflection upon themselves as a family system marginalized due to stigma and a lack of supportive resources, and second, turning outward to seek change processes that would increase their quality of life. This included forming connections with other like-minded and similarly situated individuals, and engaging proactively and assertively with educational, social and medical systems they found were not adequately meeting their needs. Notably, a key response by those families whose structure, composition and resources allowed for it was to rework dominant social norms in Canada - for example, including grandparents more directly in the direct care of the immediate family, and in embracing a model of familial attachment that recognized the need for longer term, more involved parenting than is common in neurotypical families. It also involved a process of outward-focused advocacy, which, in the words of Ungar (2008) supported the individual, family, and in some cases, ADHD

community to sometimes subversively “*navigate*” (p. 225) through challenging systems, such as the medical and educational system, in seeking sufficient resources to lead meaningful lives.

A notable finding was the call from parents and professionals for more support groups to help families share knowledge and mentor each other in the daily, lived experience of ADHD. Primarily for parent participants, but also for some of the professionals, these support groups were also considered important in helping parents work together to undertake advocacy. Such advocacy was viewed as a forum for the wider ADHD community to seek change in what they perceived as unjust policies, for example, the limited recognition of ADHD within educational legislation in Canada.

This may suggest a more extensive role for the field of social work with families affected by ADHD. This might include support to both individuals and family units, following Ungar (2008), in navigating and negotiating within social and other systems. Social workers may also play an increased role through psychoeducation and support groups, referred to in research, as forums for parents to receive education regarding ADHD and supportive interventions (Climie & Henley, 2018). There may also be an enhanced role for social workers in community-building for those affected by ADHD, helping them to forge mutually supportive connections and to develop and sustain the skills and awareness they need for effective change-oriented advocacy.

### **6.3 Ecological Resilience**

Although the focus of this research was on individual and family resilience, a key insight was that building family resilience in the context of ADHD is dependent upon adequate resources and supportive environments. For example, family-consciousness building and particularly being open and ready to understand an ADHD diagnosis and celebrate good

moments despite challenge, was apparently impeded or tempered by experiences of stigma. Families that appeared to experience significant embarrassment related to stigma were less able to “dive” into understanding and working towards positive adjustment to ADHD. In contrast, families who were able to identify, understand and had the resources to counteract the negative, potentially isolating impacts of stigma, appeared less embarrassed by an adolescent’s ADHD symptoms. In turn, they appeared more prepared to accept the ADHD diagnosis and be flexible in responding to it. Similarly, family systems in which two parents were engaged in the care of the adolescent and had sufficiently flexible work lives to respond to unexpected daily challenges, and/or who had extended family able to provide respite care, appeared to have a stronger ability than those without these supports, to practically adjust to the demands of parenting an adolescent with ADHD.

These findings appear to affirm Ungar’s work on social ecologies (2015a, 2015b) relative to the experience of resilience-building for emerging adolescents with ADHD and their families. Particularly, this current research underlined that, while personal traits such as positive mindsets and motivation favorably affected resilience, environmental factors also substantially supported families. This appeared particularly salient in families not considered resilient by participants, who appeared to lack material resources and/or support to positively counteract the effects of stigma in their lives.

Potentially supportive ecological factors that were identified in this research included social policies and programs that ensure adequate levels of respite care despite personal family circumstance, and recreational and support programs that adequately and appropriately accommodate adolescents with ADHD (including parental involvement and support). Proactive ecologically-based resources identified by the participants include educational policies that

situated ADHD as a developmental disorder for which school accommodation is presumed necessary unless otherwise demonstrated, rather than vice versa, as currently exists in Canada. This was seen as a means of reducing the burden on individual parents to advocate for specialized supports in schools. Further, proposed resources included programs that provide support and social opportunities for parents experiencing stress to share education about social stigma and build mutually supportive connections. They might include a forum for those impacted by ADHD, including adolescents and supportive others, to collectively work towards advocacy efforts redressing stigma and nurturing resilience.

The central finding of this study was that families, centrally important to adolescents with ADHD, can and do build resilience within their experience of ADHD. However, they should be understood as doing so in a manner that is responding to, and interacting with, a social and policy environment that is often experienced as unsupportive, particularly so when individual families lack stable and sufficient personal and financial resources. Accordingly, the family resilience-building described in this study might effectively be viewed as a counter measure to protect adolescents with ADHD and their family. Resilience building for these families was often a courageous, difficult set of measures, taken to promote the family's quality of life, and often that of those similarly situated, within a society in which they often felt marginalized, misunderstood and unsupported.

#### **6.4 Limitations**

This study addressed the role of the individual and family relative to resilience in ADHD. While this focus advances understanding, it is acknowledged that a risk herein is misinterpreting the centrality of the individual and family, without adequately considering their well being

relative to community, societal and policy resources that ensure accessible interventions and supports. Glossing over the key role of an adequately-funded resource system risks imposing upon parents and families an unsupported responsibility for care that is both unjust and unsustainable from systems and social justice perspectives. A key limitation of this study may therefore be that it fails to fully locate individual and family resilience within the wider social and policy systems and socio-economic disparities in which individuals and families exist.

Additional limitations of the study relate to the lack of diversity in the sample. For instance, there was a relatively high percentage of adoptive families in the sample – they composed 4/9 families, a significantly higher ratio than is typical in the Canadian population. In addition, all adult participants were from majority ethnic/cultural backgrounds and of middle socioeconomic status. A further limitation was that the sample contained only three adolescents, contrary to the initial design in which I aimed for a higher adolescent to caregiver ratio. Finally, although no substantial differences in experience and perspective across regions were noted, there were relatively fewer respondents from Alberta than Ontario. The result of the above is that while saturation was achieved, challenges in recruitment (potentially a reflection of the lack of centers and organizations which provide targeted support to families of children and adolescents with ADHD), resulted in a less diverse sample than initially had been sought. Although generalizability is not an aim of qualitative studies, it is recognized the applicability or transferability of findings may have been affected by these instances of a lack of sample diversity.

A strength and limitation of the study relates to the inclusion of professional participants. This inclusion was considered necessary due to challenges in family recruitment, and indeed this added complementary and triangulated perspectives to the data set. However, it also reduced the

sole focus on first-person adolescent and family experiences and added, in some cases, the perspectives of stakeholders who certain families felt may have contributed to resource and quality of life barriers. At the same time, ensuring multiple perspectives was viewed as beneficial in offering a range of views that represented a wider range of families and perspectives (reflective of professionals' engagement with many families across socio-demographic diversities), which is in keeping with the exploratory nature of this study.

These limitations reinforce a call for further study on the experiences of ADHD in emerging adolescence including, as noted earlier, longitudinal research that documents individual and family experience related to resilience, particularly for diverse populations. In addition, they support a call for interventional research that develops and tests interventions and policy initiatives that nurture quality of life for adolescents with ADHD, and those who care for them.

## **6.5 Recommendations**

Four recommendations emerge from this study. First, it is recommended that programs that support adolescents with ADHD and related research recognize the central role of parents and families in their lives. Further study could examine if, and if so, how, parents and families retain a more important role in the lives of emerging adolescents than is common for neurotypical peers, and how this evolves over time. Programs are needed to support this role. For example, family counselling may remain a more or equally important therapeutic option relative to individual counselling for these adolescents as they age, and include work that focuses on nurturing attachment bonds and supporting siblings and others who may become sources of support for the ADHD-affected individual in later life.

Second, it is recommended that further assistance be provided to and by support programs for families affected by ADHD. Such programs should be undertaken within a strengths-based framework that seeks to support thriving and enhancing bonds between all family members, including siblings, and within the wider ADHD community. This might include increased financial and navigational resources, as are variably provided to families impacted by other neurodevelopmental conditions such as ASD. It might also involve a greater involvement of social workers in community and awareness building. Support groups, in addition to information from other disciplines, may be an effective forum for the education of parents regarding ADHD and supportive approaches and interventions (Climie & Henley, 2018).

Third, it is recommended that ongoing advocacy and policy reflection be undertaken regarding the extent and depth of support required by adolescents with ADHD in the classroom and other community settings. Specifically, it is recommended that the economic costs of inadequately supporting those with ADHD, leading, for example, to increased rates of criminal justice involvement, be compared with the costs of enhancing classroom supports while in school. It may be effective to situate school experiences within the wider life experiences of adolescents with ADHD, including ways that adversity in school settings impacts adolescents and their family life outside of school hours.

Finally, it is recommended, following Climie and Mastoras (2015), that further research be undertaken from a strengths-based focus on child and adolescent experiences of ADHD. Interventional and longitudinal research is recommended to build knowledge regarding the experience of resilience in ADHD, with specific foci on developmental needs across ages. Such research might contribute to existing knowledge regarding the nature of resilience in ADHD and potential effective models to support resilience and Positive Youth Development. Building upon

the work of Mitchell and Climie (2017), further research is needed to explore the role of family systems in supporting resilience in ADHD, including parenting and family processes in recreational and social activities. Such research needs to examine notions of attachment in families of adolescents with ADHD, and ways that individual and family well-being can be enhanced. Addressing the social determinants of health and barriers to accessing services in future research and programs is suggested, given the significant challenges noted in this research across social strata. Additionally, further research is needed regarding ecological factors that impact adolescents and their families' experiences of ADHD, and their abilities to build resilience. This includes educational, health and social policies and programs, and wider societal discourses related to ADHD and disability.

## Chapter 7: Conclusion

Although widely researched in other fields, there has been relatively limited study of ADHD within the field of social work relative to other disabling conditions and circumstances that create risk for children and adolescents. This is surprising given the prominent role of social workers in children's services and correctional settings, in which a higher proportion of those with ADHD relative to the general population are found. It is also surprising given the focus in social work research upon both the ways that visible and invisible conditions and society's response to them can result in impediments to positive life outcomes for children and adolescents.

In conducting this study, I sought to contribute to the literature examining the experiences of adolescents with ADHD and their families. The core finding was that, despite experiences of stigma and limited social and policy support, families of adolescents with ADHD, when possible, seek to understand and build resilience to obtain optimal life outcomes for family members. They do so by: seeking to understand ADHD not only as a medical but also a social phenomenon; seeking to integrate responses and adjust internally; and acting externally to build partnerships and advocate for change. These resilience-building processes may improve families' abilities to support adolescents with ADHD, help navigate daily challenges, and find ways to thrive.

The study findings demonstrate that resilience-building of families is affected *positively* by personal resources, such as motivation by parents to not let their child "fall through the cracks" and to engage support from extended family, and *negatively* by environmental conditions, such as poverty, lack of education, insufficient resources and social isolation. The recommendations

from this research include, therefore, a call to better support families in the aim of individual and family resilience-building. This resilience-building also holds the promise of improving resilience within the wider community of individuals and families affected by ADHD. To that end, continued work is needed ameliorating social, health and educational policies and programs for adolescents with ADHD.

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## **APPENDIX A: CONSENT FORMS FOR PARENT/CAREGIVER PARTICIPANTS AND PROFESSIONAL PARTICIPANTS**

### **Letter of Information and Consent for Caregivers for Personal Participation and/or Participation of a Minor**

#### **A study about Personal and Familial Resilience for Emerging Adolescents with ADHD, their Caregivers and Supportive Professionals**

**Principal Investigator:**

Dr. David Nicholas  
Faculty of Social Work  
University of Calgary  
Central and Northern Region  
Edmonton, Alberta  
(XXX) XXX XXX  
E-mail: nicholas@ucalgary.ca

**Student Investigator:**

Claire McMenemy  
Faculty of Social Work  
University of Calgary  
Central and Northern Region  
Edmonton, Alberta  
(XXX) XXX XXX  
E-mail: tmcmenem@ucalgary.ca

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

#### **BACKGROUND**

There is increasing attention to the ways that the resilience of children and adolescent with ADHD can be nurtured. Resilience can help children and adolescent to balance the challenges of ADHD with their community, family and individual strengths. This study explores what resilience is and how it may be nurtured for emerging adolescents (aged 9-15) with ADHD. We are seeking adolescents and caregivers/parents, and the professionals who support them, as participants in this study. We are seeking participants from Edmonton, Alberta, Ottawa, Ontario and the Greater Toronto Area, Ontario.

#### **WHAT IS THE PURPOSE OF THE STUDY?**

To build knowledge and understanding regarding what resilience is, how it operates and how it can be supported in the lives of emerging adolescents with ADHD.

#### **WHAT WOULD I HAVE TO DO?**

All participants will take part in an approximately 30-minute interview. Adult participants will also be asked to complete a short demographic questionnaire about their family.

If you and your adolescent are participants in this study, you will be invited to take part in separate interviews. However, you may wish to be present during your adolescent's interview or you may wish that you and your adolescent are interviewed together. If either you or your adolescent wish one of these options, the interviews will proceed on this basis. Both adolescents and caregivers may be asked to take part in a brief follow up telephone interview if further clarification is needed.

### **WHAT ARE THE RISKS?**

There is a minimal risk of psychological distress given that you and your child will be asked questions related to personal matters, including your beliefs, emotions and experiences. Should you or your child experience distress, you may cease participation in the study at any time. We will provide you with the name of a counsellor who may be able to support you, should you wish to receive support regarding your participation in this study.

### **WILL I BENEFIT IF I TAKE PART?**

Through the study, you will be contributing to knowledge and understanding about children's and adolescents' experiences of ADHD. This has the potential to inform policy makers and program providers regarding the amount and nature of services your adolescent and family receives. You and your adolescent may also experience an increased understanding of yourselves and improve your quality of life by reflecting on your own experiences and perspectives.

### **DO I HAVE TO PARTICIPATE?**

This is a voluntary study. There is no obligation to take part in the study. If your adolescent is interested in taking part in this study, we will also be seeking their agreement to do so.

You or your adolescent may withdraw from the study at any time. You may do so by communicating with the researchers by email, phone or any other measures and indicating that you wish to withdraw. We may also find that your involvement is not appropriate in this study for example, if your adolescent does not meet the inclusion criteria. If new information becomes available that might impact your willingness to participate in the study, you will be informed as soon as possible.

### **WHAT ELSE DOES MY PARTICIPATION INVOLVE?**

Your interview will be audio taped and a transcript made. If you wish, you may receive a copy of the transcript. You may also request to receive a copy of the final report of this study.

### **WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

For taking part in the study, you and if applicable, your adolescent, will each receive a \$20 gift certificate for Chapters.

**WILL MY RECORDS BE KEPT PRIVATE?**

All information obtained through this study will be confidential. All information will be held in electronic passport protected files or in a locked cabinet. The only people who will have access to these materials are the Principal Investigator and Student Researcher. All data will be treat anonymously. The University of Calgary Research Ethics Board may also have access to any records and materials obtained during this study for its oversight role.

**SIGNATURES**

Your signature on this form indicates that you have understood to your satisfaction the information regarding your and, if applicable, your adolescent’s, participation in the research project. Your signature indicates that you agree that you and, if applicable, your adolescent, will participate as participants. In no way does this waive your legal rights nor release the investigators or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time.

If you have further questions concerning matters related to this research, please contact:

Dr. David Nicholas (XXX) XXX XXX

Or

Claire McMenemy (XXX) XXX XXX

This study has been approved by the University of Calgary Conjoint Faculties Research Ethics Board. If you have any concerns about the way you’ve been treated as a participant, please contact Research Ethics Administrators, Research Services Office, University of Calgary at (403) 220-6289/220-4283; email [cfreb@ucalgary.ca](mailto:cfreb@ucalgary.ca).

\_\_\_\_\_  
Caregiver’s Name

\_\_\_\_\_  
Signature and Date

\_\_\_\_\_  
Investigator/Delegate’s Name

\_\_\_\_\_  
Signature and Date

\_\_\_\_\_  
Witness’ Name

\_\_\_\_\_  
Signature and Date

A signed copy of this consent form has been given to you to keep for your records and reference.

## **Letter of Information and Consent for Supportive Professionals**

### **A study about Personal and Familial Resilience for Emerging Adolescents with ADHD, their Caregivers and Supportive Professionals**

#### **Principal Investigator:**

Dr. David Nicholas  
Faculty of Social Work  
University of Calgary  
Central and Northern Region  
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(XXX) XXX XXX  
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#### **Student Investigator:**

Claire McMenemy  
Faculty of Social Work  
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E-mail: tmcmenem@ucalgary.ca

This consent form is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, please ask. Take the time to read this carefully and to understand any accompanying information. You will receive a copy of this form.

### **BACKGROUND**

There is increasing attention to the ways that the resilience of children and adolescent with ADHD can be nurtured. Resilience can help children and adolescent to balance the challenges of ADHD with their community, family and individual strengths. This study explores what resilience is and how it may be nurtured for emerging adolescents (aged 9-15) with ADHD. We are seeking adolescents and caregivers/parents, and the professionals who support them, as participants in this study. We are seeking participants from Edmonton, Alberta, Ottawa, Ontario and the Greater Toronto Area, Ontario.

### **WHAT IS THE PURPOSE OF THE STUDY?**

To build knowledge and understanding regarding what resilience is, how it operates and how it can be supported in the lives of emerging adolescents with ADHD.

### **WHAT WOULD I HAVE TO DO?**

All participants will take part in an approximately 30-minute interview. Professionals will also be asked to complete a short demographic questionnaire about their experience in working with adolescents with ADHD and their families.

### **WHAT ARE THE RISKS?**

There is a minimal risk of psychological distress given that you will be asked to reflect upon your experience of working with clients who may have been experiencing challenges. Should

you experience distress, you may cease participation in the study at any time. We will provide you with the name of a counsellor who may be able to support you, should you wish to receive support regarding your participation in this study.

### **WILL I BENEFIT IF I TAKE PART?**

Through the study, you will be contributing to knowledge and understanding about children's and adolescents' experiences of ADHD. This has the potential to inform policy makers and program providers regarding the amount and nature of services children, adolescent and their families receive.

### **DO I HAVE TO PARTICIPATE?**

This is a voluntary study. There is no obligation to take part in the study.

You may withdraw from the study at any time. You may do so by communicating with the researchers by email, phone or any other measures and indicating that you wish to withdraw. We may also find that your involvement is not appropriate in this study for example, if you have experience in working only with clients who do not meet the inclusion criteria. If new information becomes available that might impact your willingness to participate in the study, you will be informed as soon as possible.

### **WHAT ELSE DOES MY PARTICIPATION INVOLVE?**

Your interview will be audio taped and a transcript made. If you wish, you may receive a copy of the transcript. You may also request to receive a copy of the final report of this study.

### **WILL I BE PAID FOR PARTICIPATING, OR DO I HAVE TO PAY FOR ANYTHING?**

For taking part in the study, you will receive a \$20 gift certificate for Chapters.

### **WILL MY RECORDS BE KEPT PRIVATE?**

All information obtained through this study will be confidential. All information will be held in electronic passport protected files or in a locked cabinet. The only people who will have access to these materials are the Principal Investigator and Student Researcher. All data will be treated anonymously. The University of Calgary Research Ethics Board may also have access to any records and materials obtained during this study for its oversight role.

### **SIGNATURES**

Your signature on this form indicates that you have understood to your satisfaction the information regarding your participation in the research project and that you will participate as a participant. In no way does this waive your legal rights nor release the investigators or involved

institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time.

If you have further questions concerning matters related to this research, please contact:

Dr. David Nicholas (XXX) XXX XXXX

Or

Claire McMenemy (XXX) XXX XXXX

This study has been approved by the University of Calgary Conjoint Faculties Research Ethics Board. If you have any concerns about the way you've been treated as a participant, please contact Research Ethics Administrators, Research Services Office, University of Calgary at (403) 220-6289/220-4283; email [cfreb@ucalgary.ca](mailto:cfreb@ucalgary.ca).

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Supporting Professional's Name

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Signature and Date

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Investigator/Delegate's Name

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Signature and Date

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Witness' Name

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Signature and Date

A signed copy of this consent form has been given to you to keep for your records and reference.

## APPENDIX B: ASSENT FORM FOR ADOLESCENTS

### Letter of Information and Assent for Minor Participant

#### **A study about Personal and Familial Resilience for Emerging Adolescents with ADHD, their Caregivers and Supportive Professionals**

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We want to tell you about a research study we are doing. A research study is a way to learn more about something. We would like to find out more about what people your age think helps them to be strong, positive and resilient. You are being asked to join the study because you are between 9-15 years old and have been diagnosed with ADHD.

If you agree to join this study, you will take part in an approximately 30-minute interview.

We hope that through this study we can learn more about what people your age think makes them strong, positive and resilient, and how they handle challenges in their lives. We hope that this may help different organizations to support you in the best ways possible. We expect that it may be interesting to think about this and to share it.

There is a small risk that you might be a bit upset by talking about challenges you experience. You can decide not to take part in this study at any time, even after you have started, if this happens. Also, we will give your caregiver the name of someone you can talk with if taking part in this study is something upsetting that you want to talk about.

Whether you take part in this study or not is up to you. You can say okay now. You can also say no. If you say okay now, you can change your mind later. If you want to stop, then all you must do is tell us you want to stop. No one will be mad if you don't want to be in the study or if you join the study and then change your mind later and stop.

Before you say yes or no to being in this study, we will answer any questions you have. If you decide to join the study, you can ask questions at any time. Just tell the researcher that you have a question.



## **APPENDIX C: INTERVIEW GUIDES**

### **Interview Guide – Adolescent**

1. Have you heard of the term resilience? People often think it means being able to be positive, strong and overcome challenges so that you can move forward.
2. Can you tell me about an adolescent you think is resilient and able to overcome challenges really well? What sort of challenges did they face? What helped them to be able to face the challenges?
3. Do you think that you are resilient? What about you helps you to be resilient? (eg. beliefs, experiences, practises, how you think about yourself) Are there things about your family that help you to be resilient?
4. Do you think there are ways that people who support you could help you to be more resilient? (eg. Doctors, counsellors, teachers, parents, cultural or spiritual organizations)
5. Is there anything else that you would like to tell me that you think is important for this study?

### **Interview Guide – Primary Caregivers**

1. What do you think it means to be resilient? People often think of it as being able to remain positive and use strengths to overcome challenges and be able to keep moving forward.
2. Can you tell me about an adolescent with ADHD whom you consider resilient? What things about them or their family helped them to be resilient? (eg. Beliefs, experiences, practices, ways they thought about themselves, relationships)
3. Do you consider your adolescent resilient? What things about them or their family help them to be resilient?
4. What do you think could help your adolescent to become more resilient? Who do you think would be important as partners in helping to nurture their resilience?
5. Is there anything else you want to tell me that you think is important for this study?

### **Interview Guide – Professionals**

1. Can you explain how you understand or think about resilience?
2. What does resilience look like in an adolescent with ADHD?
3. Can you give an example of an adolescent with ADHD whom you met who was resilient?
4. What personal or family factors helped them to be resilient?

5. Can you give an example of an adolescent with ADHD who was not resilient? What was missing for them?
6. In what ways can the resilience of adolescents with ADHD be strengthened? Who are the primary people/organizations that can help?
7. Is there anything else you may want to tell me that you think is important for this study?

## APPENDIX D: PARTIAL MEMO

“overboard”, “overbearing” “super involved” parenting emerging as connected

Denotes different type/quality of parenting than typical

Seems to have been described in interview with sense that experience others’ judgement from parenting in this way, but still do it (defiant, proud?) because know it is right for their family

Emotion in the way the words are said, almost tearful in one interview

Personal reaction to this – positively in some ways because it seemed to affirm similar experiences but also negatively – what does this mean for adolescent’s identity and development? Will need to be conscious of my reactions in analysis

What impact does lack of diversity have in this description of parenting – would people of different cultures/socio economic backgrounds/ages share this perspective of resilient parenting approach

Gerund options: parenting approach (type of actions for parenting/type of approach)

May theoretically relate to theories of Attachment – what is “attached” parenting of an adolescent with ADHD? How different than that of neurotypical peers?

May relate to experiences of stigma/social judgement/oppression – parenting like this even though parent may face the derogatory social label of being a “helicopter” parent is an act of defiance against social norms.