Resilience and Thriving Among Youth and Young Adults with Fetal Alcohol Spectrum Disorder

By

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Abstract

This manuscript-based dissertation investigated the processes of resilience and thriving among youth and young adults with Fetal Alcohol Spectrum Disorder (FASD). Following a review of relevant literature, two studies are presented. Study 1 is a quantitative study focused on resilience among youth with FASD. The purpose of Study 1 was to provide a profile of youth- and caregiver-reported resilience resources and the association between these resources and concurrently reported emotional and behavioural functioning. This study included 19 youth with FASD (aged 13 to 23 years) and their caregivers (foster or adoptive parents). Youth with FASD were reported to have comparable relational resilience resources to a typically developing normative reference group, but lower contextual resources compared to the reference group. Caregivers reported youth to have low individual resilience resources, but youth with FASD reported individual resources commensurate with the normative reference group. Early childhood adversity, age, sex, and IQ were not significantly associated with resilience resources. However, earlier age of stable caregiving placement and earlier age at FASD diagnosis were associated with greater caregiver-reported relational and contextual resilience resources. Finally, higher youth- and caregiver-reported individual resources were associated with less mental health symptomology, and higher youth- and caregiver-reported individual and contextual resources were associated with better adaptive functioning behaviour. These findings complement previous research documenting the necessity of ensuring early stable relationships for youth with FASD and permitting timely access to diagnostic services. The results also highlight the need to better understand and strengthen individual and contextual resources.

The second study is a qualitative study that explored what it means to thrive with FASD. Five youth and young adults with FASD (aged 16 to 24 years) and seven caregivers provided a

rich understanding of how thriving is conceptualized and supported among young people with FASD. Participants described individual qualities that they believed characterized a thriving youth with FASD, as well as qualities of youth environments that supported the development of thriving. Individual markers of thriving with FASD were described by six themes: *connection to others, competence and autonomy, meaningful participation, integrated identity, moving toward,* and *feeling happy*. Four additional themes reflected the importance of youth environments in supporting thriving: *context matters, affirming youth, understanding youth,* and *responsive to youth's individual needs.* Overall, thriving with FASD was conceptualized as an individualized, multidimensional, and interactive process. As the first study in this population to explore thriving, this research contributes to our understanding of how to define what it means to be successful with FASD, and how to support people with FASD to do well across the lifespan.

The findings of Study 1 and 2 both support and expand upon the existing literature, shedding light on the individual, relational, and contextual strengths of individuals with FASD and how to best support successful trajectories that matter to individuals with FASD and their families. This dissertation concludes with a discussion and integration of key findings from Study 1 and 2, including how this research informs clinical practice and future research.

Keywords: Fetal Alcohol Spectrum Disorder, developmental disability, mental health, resilience, thriving, success, strengths-based, positive youth development

Preface

This thesis is an original work by Katrina Kully-Martens. The research projects affiliated with this thesis received research ethics approval from the University of Alberta Research Ethics Board. Study 1: "Longitudinal Assessment of Individuals with PAE and FASD," Pro00057460, 29 January 2016; Study 2: "Resilience and Thriving Among Youth with Fetal Alcohol Spectrum Disorder," Pro00086177, 4 December 2018.

Dedication

For all of the incredible individuals who participated in these studies. You have all taught me more than you will ever know. Thank you for inspiring me to finally attempt my Rubik's cube.

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I am grateful to my supervisors, Dr. Jacqueline Pei and Dr. Carmen Rasmussen, for encouraging me to pursue this work, for the decade of mentorship they provided me, and for patiently supporting me through a very long journey – thank you. Additional thanks to Dr. Lia Daniels for serving on my supervisory committee and for providing such thoughtful and encouraging feedback. I would also like to acknowledge and thank the members of my examining committee, Dr. Damien Cormier and Dr. George Buck, and my external examiner, Dr. Cheryll Duquette, for contributing their time and expertise.

I am immensely grateful to the youth and caregivers who participated in this project. Thank you for seeing value in my research, for giving your time, and for sharing your experiences. I thought deeply about what you shared with me, and I carry many of your words with me to this day. During my first interview for Study 2, one of you shared with me your love of challenging puzzles, especially Rubik's cubes. I confided that I had never even touched a Rubik's cube before. "I've always been too scared to even try," I said. "I don't like failing." I was being truthful about the Rubik's cube, but I was really talking about my dissertation. It loomed before me, accompanied by endless feelings of doubt, anxiety, and at times, hopelessness. As if you could read my mind, you excitedly said, "Just think of this! I know school is important and all that. But small stuff like puzzles or whatever, if you're scared of failing, you'll never do great, right? But if you're like, 'Yeah, okay, I can take that on or whatever, even if I only get 60%,' it will just encourage you to work harder." I've thought about that every day since. Thank you.

Thank you to the Glenrose FASD Clinic and the Hinton Friendship Centre for supporting my research. I would also like to thank my colleagues for their emotional and academic support

throughout this journey. Many aspects of these studies would not have been possible without the highly organized efforts of Kathryn Kryska and Allison McNeil – thank you both. I am also grateful for the generous funding provided by the Social Sciences and Humanities Research Council of Canada (SSHRC), the Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD), Kids Brain Health Network, and the University of Alberta through scholarships and graduate assistantships throughout my degree.

I worked on this project while living in four different cities across Canada. I worked as I looked out my office window into cityscapes, forests, and mountain views. My incredible partner, my phenomenal parents, and my amazing family never once wavered in their support during this fairly long series of location changes and my seemingly never-ending quest to study and write. The only time they ever questioned or contradicted me is when I questioned my own ability to continue. Because of their support, I was able to actualize what was always within me. I will forever be grateful, and never quite able to express just how much. Thank you.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction

Prenatal alcohol exposure (PAE) is a leading risk factor for neurodevelopmental challenges. An estimated 2 to 5% of North Americans have a Fetal Alcohol Spectrum Disorder (FASD; May et al., 2018; Roozen et al., 2016), an umbrella term that describes the range of life-long cognitive, behavioural, and physical challenges that result from PAE (Cook et al., 2016).

Fetal Alcohol Syndrome (FAS), the first PAE-related condition to be formally identified, was initially described five decades ago (Jones & Smith, 1973; Jones et al., 1973; Lemoine et al., 1968). Since then, significant effort has been devoted to understanding the myriad of neurobehavioural challenges and developmental outcomes associated with FASD. FASD is a complex and heterogenous developmental disability. Although there is significant variability in functioning between and within individuals with FASD (Ali et al., 2018), affected individuals experience a range of mild to severe difficulties in numerous domains of functioning, including general cognitive ability, academic achievement, learning, memory, attention, executive functioning, affect regulation, and adaptive functioning (Cook et al., 2016; Mattson et al., 2019). Mental health and neurobehavioural comorbidities are also common (e.g., Kambeitz et al., 2019; Pei et al., 2011). Individuals with FASD are also more likely to experience postnatal adversities that can negatively affect development, including exposure to abuse, neglect, and violence; instability in caregiver relationships; and having parents with substance abuse or mental health problems (Kambeitz et al., 2019; McLachlan et al., 2015, 2020; Streissguth et al., 2004).

Cross-sectional and longitudinal research has demonstrated that individuals with FASD are more likely to encounter a range of challenges as they progress through development in comparison to their typically developing peers. These challenges, often referred to as *secondary disabilities* or *adverse outcomes*, include educational disruption (e.g., academic incompletion,

suspension), problems living independently, difficulty securing employment, legal troubles (e.g., criminal offending, victimization, incarceration), and substance misuse (Clark et al., 2004; Lynch et al., 2015; McLachlan et al., 2020; Rangmar et al., 2015; Streissguth et al., 2004). Secondary disabilities tend to intensify and accumulate with age as demands and expectations on individuals increase, and as relational and contextual supports become less available (Burnside & Fuchs, 2013; Kambeitz et al., 2019; McLachlan et al., 2020; Streissguth et al., 2004). The development of secondary disabilities is believed to result from the complex interaction between the individual, their relationships, and their environment (Clark et al., 2004; McLachlan et al., 2020; Streissguth et al., 2004). For example, primary disabilities resulting from PAE may interact with environmental adversity to increase the risk of experiencing secondary disabilities. On the other hand, the risk of developing secondary disabilities may be attenuated when primary disabilities are adequately supported in the environment, such as through timely access to diagnosis and individually-appropriate services (e.g., Currie et al., 2016; Streissguth et al., 2004), or when adversity is met with early stability in relationships.

Research on FASD to date has largely focused on deficits and challenges, and has demonstrated that the consequences of PAE can be profound. This type of research was a logical starting point for several reasons. First, it improved understanding of PAE by delineating the nature of related conditions. Second, this research guided and supported efforts intended to improve outcomes, such as standardizing assessment and diagnosis; developing interventions and educational practices; lobbying for attention, understanding, and funding across service sectors and social systems; and developing and mobilizing prevention strategies. Yet, due in part to this research focus, the predominant discourse surrounding FASD has reflected a deficit-perspective centering on pathology.

CHAPTER 1: INTRODUCTION

Researchers, clinicians, families, and individuals with FASD have begun to assert that an understanding of FASD limited to deficits and challenges is incomplete. Not everyone with FASD will experience negative, or at least uniformly negative, outcomes (e.g., Duquette et al., 2006; Kapasi et al., 2019; Knorr & McIntyre, 2016). FASD is complex, and the individuals affected by FASD are not one-dimensional; nor are the relational and social systems in which individuals with FASD are embedded. Furthermore, according to relational-developmental systems theory, which is a predominant orientation within developmental psychology, growth and development within every individual and system is continuous (e.g., Lerner et al., 2015; Masten, 2014). Protective forces counterbalance risk; thriving counterbalances languishing. All individuals are capable of navigating the balance between these forces. Therefore, there is an entirely other facet of the heterogenous and complex experience of having a disability like FASD: strengths, growth, and the capacity of individuals and families to adapt and move toward psychological and physical health. This "other side" of FASD is only beginning to be addressed – for example, through intervention research (Paley & O'Connor, 2011; Peadon et al., 2009; Wheeler et al., 2013), research examining individual and caregiver strengths (Kapasi & Brown, 2017; Mariasine et al., 2014), and studies examining resilience (e.g., Knorr & McIntyre, 2016; Rogers et al., 2013) and factors associated with positive outcomes such as school persistence (e.g., Duquette et al., 2006) and employment success (e.g., Kapasi et al., 2019).

It is important to improve our understanding of the range of possibilities that are experienced by individuals with FASD and their families. This will help to better tailor expectations and goals, encourage growth, inform intervention, provide hope, and ultimately facilitate a necessary perceptual shift: the challenges associated with FASD are life-long and real, but development and change is continuous, multifaceted, and possible.

In order to support individuals with FASD to develop healthily, even in the midst of challenges, it is essential to understand how and why different individuals have different experiences of counterbalancing adversity. We need to be able to identify and understand the individual, relational, and contextual factors that protect individuals from harm and potentiate adaptation and growth toward healthy outcomes; that is, the resources associated with *resilience*. This will help key stakeholders and systems support the development of these assets. I believe it is also important to ask what it would mean for an individual with FASD to self-actualize and develop optimally. In other words, to understand what it would look like to go beyond a better-than-expected level of functioning; to think beyond avoiding adverse outcomes and begin to understand what it would mean to *thrive.*

Purpose and Outline of Dissertation

This manuscript-based dissertation examines resilience and thriving among youth and young adults with FASD. This supports a necessary shift towards reducing the focus on deficits and negative outcomes by approaching research from a strengths-based, growth-oriented lens that focuses on how individuals with FASD and the relational and contextual systems in which they are embedded navigate toward healthy outcomes.

The dissertation includes three papers. The first paper is a literature review focusing on two separate bodies of research: resilience in development and thriving in development. The purpose of this narrative review was to examine the extant literature in each of these areas of study, and the extent to which FASD and other complex developmental disabilities are represented in the literature. This foundation ultimately guided the development of the subsequent two papers.

The second paper is a quantitative study. The purpose of this study was to describe the profile of individual, relational, and contextual resilience resources reported by youth with FASD (aged 13 to 23 years) and their caregivers and examine how these resources related to early childhood adversity, potential protective factors, and concurrent emotional and behavioural functioning.

The third paper is a qualitative study that goes beyond the study of resilience to explore the concept of thriving – that is, optimal development. The purpose of this study was to understand what it means to thrive with FASD from the perspectives of youth and young adults with FASD (aged 16 to 24 years) and their caregivers. Guided by positive youth development and relational-developmental systems theory, I used a basic qualitative approach to explore how thriving is conceptualized and supported among young people with FASD. To my knowledge, this is the first investigation of thriving among individuals with FASD, and one of the first in the developmental disabilities literature in general.

All three papers presented in this dissertation are unified by a common premise. As a whole, this dissertation is founded on the idea that gaining a balanced and integrated understanding of FASD (i.e., both strengths and challenges) by focusing on individual and systemic capacities, strengths, and potential for growth is required to move the field forward and ultimately provide the best support for individuals with FASD and their families. This approach supports diverse individuals, who are more than their diagnosis, in making the countless decisions required of them. It provides a foundation for hope in a body of knowledge.

Researcher Positionality

This dissertation includes both a quantitative and a qualitative study. In the case of qualitative inquiry, it is especially important to acknowledge that the researcher affects and is

affected by the research process (Probst & Berenson, 2014) and thus can be seen as the "primary instrument" that drives the study (Merriam & Tisdell, 2016). In order to understand how certain conclusions were reached, primary researchers need to be explicit about their experiences, beliefs, biases, and assumptions which form the lens through which they interact with all aspects of the study. My background has inextricably shaped my approach to studying resilience and thriving among young people with FASD. I will now highlight how my personal experiences, my professional training as a clinical researcher and psychologist, and my own epistemological beliefs shaped the way I approached and interacted with this topic.

Personally, I identify as a white, cisgender, heterosexual woman. I have had abundant privilege in education, finances, family stability, and physical health. Like anyone, I have experienced periodic challenges that have made pursuing my goals difficult at times. However, I have never had significant and sustained difficulties with learning, communicating, or regulating my behaviour. My skills, strengths, and interests have always been valued by my community and by society. I have not generally experienced stigma or marginalization in relation to my cultural background, sexuality, behaviour, or mental health status. I do not have close family members or friends with significant disabilities. Thus, I cannot relate directly to many of the experiences of the individuals I work with and study. Something I believe I share with the people I work with is the desire to grow, change, and be seen as healthy and successful on my own terms. Because of my background, I have been afforded much greater power than many others to claim my own choices and story as successful. For most of my life, I have grappled with the fact that I have done nothing to deserve being born into such privileged circumstances. As an adult, I find myself striving – in an effort to transform this sense of guilt into useful and meaningful action – to find productive ways to use my privilege to help others. This is what led me to pursue a career as a

psychologist and the study of the transformative processes of resilience and thriving among individuals who may experience marginalization in many areas of their lives.

My early professional experiences also played a role in my desire to pursue this research. In my early 20s, I worked as a research coordinator. I began to meet families raising children with FASD from around my province. It did not take long for me to notice resonant calls from the community for research that explored the full complexities of FASD. Many parents, grandparents, and family members told me about their struggles in raising their cherished children within communities that were not accepting of their differences; within a healthcare and educational system that did not fully *see* them. One woman told me that in her culture, having FASD was not seen negatively. It was a special gift; a burden given to be transformed. These experiences had a profound effect on me. I decided I wanted to devote my life to understanding how every individual's unique gifts – including struggles – can be supported and transformed by leveraging each person's innate capacity and desire for growth.

My experiences as a research coordinator ultimately led me to pursue graduate school in School and Clinical Child Psychology. I now work as a Registered Psychologist, primarily with children, youth, and young adults. My training was broad-based, with a strong developmental focus. My clinical practice continues to be influenced strongly by humanistic, relational-developmental systems, and social-ecological systems theories. I believe that all individuals are capable of growth and are inherently self-righting. I think that even "maladaptive" behaviours or beliefs reflect the meeting of a need or a tendency toward adaptation. I believe individuals must be understood in context, and that helping people – especially children and youth – requires intervening within their relationships and environments. I believe that plasticity exists both within each individual and within his or her relational and contextual systems, though it is not

limitless. I believe that every person has innate strengths and capacities that can be built upon, though I do not discount the importance of addressing deficits. My research is explicitly and implicitly guided by similar theory and approach. My experience of practicing psychology has also taught me that quantitative and qualitative sources of information are equally important. I strive to be intentional and reflective in how I understand numbers and scores within individual context and personal narrative. In both my clinical work and my research, I strive to constantly question whose knowledge I am privileging.

Finally, my individual researcher worldview (i.e., beliefs about the nature of knowledge) also bear on this research. I identify as a pragmatist, meaning that I value both subjective and objective knowledge, and I embrace plurality in methods and philosophies in order to do "what works" to respond to particular research questions (Kaushik & Walsh, 2019; Tashakkori & Teddlie, 2003). In developing these studies, I was driven by questions I was curious about, what I perceived to be the needs and questions of the community (based on clinical work, research literature, and grey literature), and the extent to which the existing research literature had addressed these questions. My research approach was informed by the best ways to answer my research questions rather than being driven by a specific epistemology or methodological preference.

I believe that clinical research should endeavor to be responsive to the needs of the community being studied. Although my career is just beginning, over the last 10 years, I have been lucky to hear the stories of many individuals with FASD, and the stories of their caregivers and families. Each story has contained frustration and joy; loss and connection; tragedy and strength; challenges and successes. Each individual and family has wanted this balance to be acknowledged; to be understood as complete, complex human beings. I truly believe that this

research represents a joint expression of community needs and desires, my own intellectual/professional interests and passions, and where research and clinical practice needs to grow.

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Chapter 2: Resilience and Thriving in Development: A Literature Review

For decades, clinical research with developmental populations has focused on how the experience of adversity contributes to the development of psychopathology. However, in the 1970s, researchers began to notice an interesting phenomenon: a proportion of children exposed to significant risk were developing competently (Garmezy, 1974; Rutter, 1979). This phenomenon became known as *resilience*. The study of resilience represents a shift from solely considering pathology to understanding how adversity can be "averted, resolved, or transcended" (O'Dougherty Wright et al., 2013, p. 15). This position is fundamental in supporting prevention and treatment efforts for children and youth at-risk (Masten & Cicchetti, 2016). Decades later, and in part stimulated by resilience research, groups of researchers from positive youth development and positive psychology movements began to ask how youth manage to surpass competent development to *thrive* (Benson & Scales, 2009; Lerner et al., 2003).

The terms *resilience* and *thriving* are often used interchangeably; however, they are separate constructs. Resilience is typically defined as competent adaptation amidst adversity, whereas *thriving* implies going beyond adequate functioning and the absence of pathology into the realm of optimal functioning (Sesma et al., 2013). In addition, unlike resilience, thriving is not specific to those exposed to significant risk.

The study of resilience and thriving has contributed significantly to our understanding of how to promote psychological health across the lifespan. Unfortunately, these bodies of literature have focused almost exclusively on neurotypical individuals, with little consideration of how resilience and thriving operate in populations with developmental disabilities. By definition, developmental disabilities challenge "competent" development, which is a core feature of

resilience and a logical precursor to thriving. Given this, it is possible that resilience and thriving may look different in the context of developmental disability.

The purpose of this narrative review paper is to review theoretical and empirical perspectives on resilience and thriving to provide a foundation for the study of these constructs in complex developmental disability populations, specifically Fetal Alcohol Spectrum Disorder (FASD). As noted, there is a lack of resilience and thriving research involving individuals with developmental disabilities in general, let alone FASD. To remain focused while still providing useful potential analogues for the study of resilience and thriving in FASD, I have included Intellectual Disability (ID) and Autism Spectrum Disorder (ASD) in my review. Although very different from one another, these disorders have relatively similar prevalence, are congenital (or have very early onset), and usually result in wide-ranging cognitive, behavioural, emotional, social, and adaptive functioning challenges. This review will focus on the developmental period of childhood to emerging adulthood (approximately age 5 to 25 years).

This paper is divided into two main sections: one dedicated to resilience, and one to thriving. Within each section, I begin by reviewing relevant theory and the broader empirical literature. I then explore the extent to which FASD, ID, and ASD have been represented within the literature, and make suggestions for how to move the study of resilience and thriving forward in developmental disability populations.

Part One: Resilience in Development

Conceptualizing Resilience: Theoretical Underpinnings

Resilience is a complex construct. Its conceptualization has evolved to focus on understanding individual and environmental risk, protective, and promotive factors and how they interact as part of a dynamic, multi-level system. An extensive literature review and concept

analysis of over 270 articles defined resilience as "the process of effectively negotiating, adapting to, or managing significant sources of stress and trauma. Assets and resources within the individual, their life, and environment facilitate this capacity for adaptation and 'bouncing back' in the face of adversity" (Windle, 2011, p. 152). This definition reflects a predominant theory of resilience: the *relational-developmental systems* perspective (Lerner et al., 2013; Masten & Cicchetti, 2016). This lens incorporates aspects of several theories including Bronfenbrenner's ecological theory (1977), developmental systems theory (Benson et al., 2006), family systems theory (Goldenberg & Goldenberg, 2013), developmental psychopathology (e.g., Cicchetti, 2006) and resilience theory (e.g., Cicchetti, 2010; Masten, 2014).

Resilience from a relational-developmental systems perspective is conceptualized as a dynamic *process,* not an outcome or a fixed one-dimensional trait. The earliest resilience studies labeled resilient individuals as "invulnerable" (Anthony, 1974), suggesting that the capacity to evade risk was absolute and unchanging. Present conceptualizations suggest that positive adaptation amidst adversity is ongoing and interactional because the "systems involved in the capacity for adaptation are developing and changing" (Masten & Cicchetti, 2016, p. 5). As development progresses, new vulnerabilities and strengths can emerge. Thus, individuals may be more or less resilient at different times across the lifespan, although resilience at one point in time tends to predict future resilience. Furthermore, what it means to be resilient as a young adolescent may be different than what it means to be resilient as an older adolescent or emerging adult. Additionally, because resilience is an active process, resilience must result from *exposure* to risk and not merely *avoidance* of risk. Resilient individuals successfully engage with their environment to mobilize resources to buffer against adversity (Masten, 2014).

Resilience depends on many interacting systems. Early studies focused mainly on identifying individual qualities of resilient children. Presently, three general sets of factors are commonly seen to foster resilience: individual qualities, relational or family characteristics, and qualities of the broader environment (Masten & Cicchetti, 2016). These systems of factors are dynamic and intricately interconnected; each system can influence the resilience of another. Resilience doesn't mean individuals are invulnerable or unaffected by adversity; rather, it means they are able to adapt to the environment by leveraging these internal and external resources.

Importantly, resilience is a superordinate construct that requires both: 1) the presence of competent functioning; and 2) exposure to risk or adversity known to interfere with adjustment (Masten, 2018; Masten & Cicchetti, 2016). I will address each of these in turn.

Competent Functioning: Healthy Adaptation and Positive Development

There is some debate as to what constitutes resilient or competent functioning. Many definitions of competent functioning reflect age-related and culture-bound standards of behaviour known as developmental tasks (Masten et al., 2006). For example, in studies of predominantly North American children and youth, these tasks include: academic achievement (e.g., good grades/test scores, graduating high school, post-secondary education), behavioural competence (e.g., rule-abiding, prosocial behaviour), social competence (e.g., positive peer relations, peer acceptance), secure attachment with caregivers, involvement in activities (e.g., age-appropriate involvement in sports, extracurricular activities, community service), normative mental health, and the absence of negative behaviour (e.g., risk-taking behaviour, criminality; Luthar & Cicchetti, 2000; Masten et al., 2006). In recognition of the inherent social/cultural bias of these adaptation criteria, some researchers have endeavored to document cultural and socioeconomic variations in healthy adaptation (e.g., Ungar, 2008, 2011). Their work

underscores the importance of contextualizing resilience – for example, by focusing on domains of competence that are relevant and valued to the individuals or social/cultural groups being studied.

Although there is a general consensus that overt displays of competence (i.e., external indicators of adaptation, described above) should be included in the assessment of resilience, there is some debate as to whether internal adaptation (i.e., positive psychological well-being, mental health) should be considered an indicator of resilient functioning versus a predictor or moderator of resilience. A child may demonstrate overt social competence, yet may struggle with symptoms of internalized distress such as depression and anxiety (Luthar & Zigler, 1991). This pattern has been documented among many at-risk groups of children including maltreated children (Farber & Egeland, 1987), inner-city youth (Luthar, 1991), and children of alcoholics (Zucker et al., 2003). In fact, some researchers have suggested that unacknowledged internal distress among children who may appear externally resilient may actually derail resilient trajectories, underscoring the need to consider both external and internal vulnerabilities and strengths (Luthar, 2006; Luthar & Cicchetti, 2000).

It is also important to consider multiple domains of functioning when defining healthy adaptation. Typically developing children who do not experience significant adversity do not manifest uniformly positive or negative adaptation across all areas of development. Likewise, children at-risk will also have strengths and difficulties. This brings into question how many domains of functioning must be satisfied as competent in order to be considered resilient.

Threats to Adaptation: Risk

Risk is defined in terms of probability: a high-risk exposure carries high odds for measurable maladjustment in crucial domains of functioning (Luthar, 2006; Masten & Cicchetti,

2016; Obradović et al., 2012). Acute or chronic accumulation of risk is related to myriad negative outcomes, including poor academic achievement, school dropout, substance misuse, behavioural problems, violence, justice-involvement, and psychopathology (for reviews, see Jaffee, 2017; Obradović et al., 2012). Importantly, children considered high-risk in the broader resilience literature are those who have been exposed to environmental factors that tend to impede healthy adaptation, not children who have vulnerabilities related to specific clinical presentations (e.g., developmental disabilities).

Most early resilience studies focused on isolating single risk factors to study resilience, such as exposure to violence, poverty, or parent mental illness (e.g., Anthony, 1974; Garmezy, 1987; Rutter, 1979). However, risk factors tend to co-occur, and different risk factors tend to predict similar problems. Therefore, researchers shifted to examining cumulative risk. When several risk factors co-occur, particularly when risks are chronic or severe, outcomes tend to be worse than when any of these risks are isolated (Evans et al., 2013; Obradović et al., 2012). A variety of threats to normative development have been considered in the resilience literature. Two major categories include biological and environmental risk.

Biological Risk

Primary biological risk factors include low birth weight, prematurity, and congenital defects or disorders (Zolkoski & Bullock, 2012). These conditions may be more likely to occur in mothers who are low-income, who use drugs or alcohol during their pregnancies, and do not receive prenatal care or appropriate nutrition. There is also increasing understanding of how genetics and epigenetics contribute to risk and the development of negative outcomes, but this is beyond the scope of this paper (see Cicchetti, 2010; Masten & Cicchetti, 2016).

Environmental Risk

Common environmental risk factors include poverty, homelessness, poor parental education, family conflict, exposure to domestic or community violence and aggression, maltreatment (i.e., abuse, neglect), being raised by a single parent or non-biological parents (e.g., foster care), and parental psychopathology (Masten & Cicchetti, 2016; Rutter, 2013). Less common risk factors include community-level traumas associated with war and natural disasters.

Promotive and Protective Factors

Promotive and protective factors are individual or environmental factors that predict positive adaptation and development (Masten, 2018; Masten & Cicchetti, 2016). A factor is designated promotive or protective based on its function in context; a given factor can be both promotive and protective, depending on the situation and the outcome in question (Masten & Tellegen, 2012). Promotive factors reliably predict positive development for all individuals, regardless of level of risk exposure. Protective factors predict positive adaptation in the presence of risk, functioning by reducing the probability that exposure to risk will result in negative consequences. In other words, a protective factor would have a greater beneficial effect on a child identified as high-risk than one who is low-risk. However, there is significant overlap between factors considered protective and promotive. Across decades of research, a fairly consistent set of promotive and protective factors have emerged. Although these factors do not operate independently, they can be roughly grouped into: 1) individual and 2) environmental promotive and protective factors.

Individual Promotive and Protective Factors

Longitudinal research has revealed numerous individual characteristics of young people who adapt well despite exposure to significant adversity (for reviews, see Benard, 2004; Masten

& Cicchetti, 2016; Werner, 2000; Zolkoski & Bullock, 2012). These characteristics fall into several broad categories, described below.

Social Competence. Resilient children and adolescents tend to be characterized by high social responsiveness (i.e., able to elicit positive responses from others) and sensitivity (Garmezy, 1993), strong communication abilities (Werner & Smith, 1982), and qualities of caring and compassion. They tend to have easy-going temperaments (e.g., Luthar & Zigler, 1991; Werner & Smith, 1982) and are more extraverted (e.g., Reed-Victor & Stronge, 2002), agreeable, and socially-oriented (Luthar & Zigler, 1991; Masten, 2001, 2007). They seek out others for support, enjoy social interaction, interact positively with others, are helpful and cooperative, and make friends easily. Among children detached from normal social circumstances (e.g., street-involved youth), understanding social norms and regulating oneself socially to adjust public behaviour may be another resilience resource (Malindi & Theron, 2010; Ungar, 2008).

Mastery Motivation and Self-Efficacy. Mastery motivation – the satisfaction we derive from our own agency and accomplishments – is a "powerful reward system for adaptation and learning" (Masten & Cicchetti, 2016, p. 21) that has been linked to resilience (Masten, 2014). Self-efficacy theory (Bandura, 1997) and intrinsic motivation (Ryan & Deci, 2000) describe similar concepts regarding the phenomena of motivation for learning and adapting. Resilient children and youth tend to report high self-efficacy, an internal locus of control (Garmezy, 1993; Masten, 2001), and a strong sense of agency and desire for mastery (Masten, 2014).

Self-Regulation. Self-regulation of emotions, behaviour, attention, and cognition is critical to achieving developmental competence in typical circumstances as well as under conditions of adversity (e.g., Artuch-Garde et al., 2017; Buckner et al., 2003; Rydell et al.,

2003). Self-regulation is important because it allows individuals to evaluate their environments, control how to respond, evaluate outcomes of their reactions, and revise their plans and courses of action. This ultimately facilitates competent deployment of adaptive behaviour, goal setting and attainment, problem-solving, decision-making, and other key developmental tasks (McClelland et al., 2018).

Problem-Solving. Problem-solving ability has long been identified as a critical factor in healthy adaptation and development (Luthar, 2006; Masten & Cicchetti, 2016). Resilient individuals tend to be confident in their ability to solve problems and overcome obstacles (Werner, 1993). They are more likely to be open to experiences (i.e., they are active and learn well and eagerly) and tend to be goal-oriented. They are good at planning, are persistent, and complete tasks independently. Werner and Smith (2001) found that resilient individuals tend to take advantage of opportunities and resources around them. They demonstrate skills in critical thinking, resourcefulness (or "street smarts"), and can think flexibly.

Intelligence. Among children from high risk backgrounds, higher overall cognitive ability generally predicts better school performance (Masten & Tellegen, 2012; Werner & Smith, 2001), fewer mental health diagnoses and behavioural problems, and better adaptive functioning (Malcarne et al., 2000). Together with problem-solving, general cognitive ability may facilitate resilience along several pathways, including by supporting school success and engagement, prosocial peer affiliation, and self-regulation skills. Healthy cognitive development is enhanced by other protective factors such as community resources (e.g., better schools, early intervention programs) and positive parent-child interaction (Masten & Cicchetti, 2016).

Positive Sense of Self and Future. Optimism and positivity have also been associated with emotional, physical, and social health in times of stress (Werner & Smith, 2001). Resilient

children and youth tend to possess a solid and positive identity, positive self-image, and positive self-appraisal (Benard, 2004). They also tend to be independent and self-reliant. Werner (2000) suggested that resilient children perceive their difficult experiences constructively and tend to view life from a more positive perspective. Having a positive future outlook and hope (Gilman et al., 2006; Schmid et al., 2011) may also be protective amidst adversity.

Sense of Purpose and Meaning-Making. Possessing faith, hope, and the belief that life has a purpose has been described as life-sustaining in times of adversity (Masten, 2009; Werner & Smith, 2001). Associated qualities of being goal-oriented, having personal determination and perseverance (Smokowski et al., 2000; Williams et al., 2001) and a strong sense of one's future (Hass & Graydon, 2009; Williams et al., 2001) also protect against adversity. Furthermore, the ability to make meaning out of suffering and transform this meaning into a component of a healthy identity or self-narrative may also be an important aspect of resilience following negative life experiences (McLean & Pratt, 2006).

In summary, individual characteristics play an important role in promoting positive development amidst adversity. However, they account for less variability in child outcomes than broader systemic factors within the environment, discussed next.

Environmental Promotive and Protective Factors

Environmental factors can provide a powerful inoculation against the negative effects of adversity. I've categorized these broadly into four domains: caring relationships, positive school experiences, high expectations, and opportunities for participation and contribution.

Caring Relationships. Close, supportive, and nurturing relationships across the lifespan are perhaps the most potent of all promotive and protective influences (Afifi & MacMillan, 2011; Bellis et al., 2017; Benzies & Mychasiuk, 2009; Masten & Cicchetti, 2016; Werner, 2013).

A primary avenue for nurturing caring relationships is within families. In fact, findings from the National Longitudinal Study of Adolescent Health found that a positive parent-youth relationship was the most consistent protective factor among 90,000 adolescents surveyed and 20,000 students interviewed (Benard, 2004). Among children who have been abused or neglected, the stable and supportive presence of at least one caregiver offers strong protection against negative outcomes (Collishaw et al., 2007; Herrenkohl et al., 1994) and is related to better adjustment in home and school settings (Rosenthal et al., 2003). Secure attachment with a caregiver provides nurturing and safety, but also supports learning, exploration, and the development of self-regulation skills, all of which serve important functions in healthy adaptation (Thompson, 2000). Secure parent-child relationships also provide the foundation for the development of other relationships, such as those with peers, teachers, and romantic partners (Sroufe, 2005). Several qualities of families have also been associated with resilience, including family warmth, cohesion, structure, emotional support, positive styles of attachment, and stability (Benzies & Mychasiuk, 2009; Masten, 2018).

Although a strong caregiving relationship is important, high-quality and supportive relationships with other adults also appear to confer protection (Shonkoff & Garner, 2012). Children who develop supportive relationships with warm, nurturing adults – teachers, coaches, mentors, caseworkers, therapists – tend to be less likely to engage in risk behaviours and more likely to demonstrate competent adaption into adulthood (Brown & Shillington, 2017; Jones, 2011; Werner, 2013). Importantly, the *quality* of youth-adult relationships may be more important than the *quantity* of time spent together in predicting healthy outcomes (Ungar, 2013).

Positive School Experiences. Schools serve multiple functions in the development of resilience (Ungar et al., 2019). At school, youth develop academic, cognitive, and life skills that

form the basis of competent adaptation, including self-regulation, social competence, and problem-solving. Schools are a place where youth can set goals, take risks, explore their talents, and experience mastery (Gilligan, 2000). Schools also provide environments to develop supportive peer and adult relationships (Ungar et al., 2019). Peer acceptance, positive peer relationships, and belonging to a peer group whose members do not engage in risk behaviours may also buffer against adversity (Benzies & Mychasiuk, 2009; Perkins & Jones, 2004). Positive school values and school climate can contribute to positive outcomes as students internalize the school's values (Aldridge et al., 2016; Perkins & Jones, 2004). Having positive school experiences fosters an attachment to school, which also supports resilience. In fact, McNeely and colleagues (2002) found that adolescents who reported feeling connected to school were less likely to use substances, demonstrate conduct problems, become pregnant, or experience emotional distress. School-based resilience resources may be especially important in the face of family-level adversity (e.g., abuse, un-involved caregivers; Liebenberg et al., 2016).

High Expectations. The presence of clear, consistent, and developmentally-appropriate expectations and structure within families, schools, and communities is another protective factor (Zolkoski & Bullock, 2012). High expectations in families and youth-adult relationships can foster feelings of self-worth and competence and help youth realize their strengths (Benard, 2004), especially when parents believe that their children can be successful and communicate these expectations in a supportive and accepting manner (Brooks & Goldstein, 2001). Within schools, demonstrating high expectations along with appropriate supports is related to lower drop-out rates and higher post-secondary attendance (Brooks, 2006).

Opportunity. Parents, schools, and communities can foster resilience by providing youth multiple avenues for developing interests and talents, advocating for greater and varied learning

experiences, and access to services (Benard, 2004; Ungar et al., 2019). Opportunities to participate and contribute provide arenas for youth to develop other internal and external resilience resources, including social competence, communication skills, problem-solving, decision-making, autonomy, and supportive relationships. In studies of former foster youth, those characterized as resilient reported being heavily involved in schools and communities (e.g., volunteering; participation in church activities, hobbies; Hass & Graydon, 2009). Relatedly, resilient youth tend to demonstrate a strong commitment to helping others and giving back to the community (Hass & Graydon, 2009).

Challenges and Complements to Relational-Developmental Systems Resilience Theory

Some have argued that a relational-developmental systems theory of resilience fails to adequately consider individual and contextual variation (Ungar, 2004, 2011). As described previously, individuals are considered resilient if they are able to cope within the boundaries of competent functioning. (Harvey & Delfabbro, 2004; Luthar & Cicchetti, 2000; Masten et al., 2006, 2009). Markers of competence are framed as objective and universal, when many are actually socially constructed and vary cross-culturally (Ungar, 2004, 2008). Constructivist scholars assert that typical definitions of resilience are presumptive about what constitutes good outcomes or successful adaptation and are "prescriptive and ability-centric" (Hutcheon & Lashewicz, 2015, p. 43) in that they dictate how competent individuals should function (Hutcheon & Lashewicz, 2014). It is possible that individuals can have different and equally successful ways of coping with adversity, even if these methods do not conform to normative standards (i.e., "hidden resilience," Malindi & Theron, 2010; Ungar, 2006). These scholars advance a social-ecological theory of resilience. This is not a wholesale rejection of contemporary resilience theory; rather, proponents argue that a relational-developmental systems

approach to resilience can be expanded upon to be more inclusive. For example, the social-contextual differences that result in differential allocation of resilience resources between minority and majority groups should be acknowledged. Individuals should also have the power to judge the health of their own outcomes and ability to be resilient, rather than being held solely to normative standards. Although social-ecological resilience theory has been mainly applied cross-culturally, the same principles can apply within other minority populations, such as those with disabilities.

Resilience Amidst Developmental Disability

To date, resilience research has focused primarily on youth who are developing typically amidst environmental adversity. Children with learning disabilities (LD) have also been included in the study of resilience, perhaps because of the significant overlap between exposure to risk and learning challenges (e.g., Raskind et al., 1999; Werner, 1993). Just as in the broader resilience literature, individual factors such as problem-solving skills, self-efficacy, and self-esteem; and environmental factors such as supportive relationships and positive school experiences have been associated with resilient trajectories for young people with LDs (see Murray & Doren, 2013). However, several studies have documented protective factors that appear to be more specific to the experience of having an LD (e.g., Goldberg et al., 2003; Miller, 2002; Piers & Duquette, 2016), highlighting the importance of examining resilience within the context of different clinical disorders. Murray and Doren (2013) summarized these as: 1) awareness and acceptance of one's disability; 2) finding and using strategies to overcome challenges associated with disability; 3) focusing on strengths; 4) focusing on mastery goals over performance goals; and 5) intentionally seeking environments and resources that support optimal performance.

Individuals with complex developmental disabilities like FASD, ID, and ASD typically experience learning difficulties. However, the nature and functional impact of the disability associated with FASD, ID, and ASD is typically much more complex than LD. Individuals with complex developmental disabilities tend to experience a broad range of cognitive impairments as well as behavioural, emotional, and physical challenges. Therefore, the ability to reach competence (i.e., resilience) is inherently compromised across multiple domains. Studies of resilience within populations with developmental disabilities have focused predominantly on the resilience of caregivers and family members (e.g., Bekhet et al., 2012; Peer & Hillman, 2014) and not on individuals themselves. There is comparatively little research focused on individual and environmental protective factors among those with complex developmental disabilities.

Some protective factors appear to be consistent between those with developmental disabilities and the broader resilience literature. For example, supportive relationships are an important protective factor in both literatures (e.g., Duquette et al., 2006; Hall & Theron, 2016; Streissguth et al., 2004). However, among developmental disability populations, certain protective factors may differ in quality, intensity, or the strength of their influence in the resilience process. For example, an additional element of relational support that may be key to supporting resilient outcomes among those with complex developmental disabilities is caregiver advocacy (Duquette & Stodel, 2005; Duquette et al., 2006). As another example, having support at school is a protective factor for both children with and without developmental disabilities, but children with developmental disabilities require a greater diversity and intensity of supports to facilitate successful outcomes compared to their typically developing peers (e.g., Duquette & Stodel, 2005; Gilmore et al., 2013). Other protective factors may function quite differently in developmental disability populations compared to typically developing youth. As previously

discussed, this reflects the fact that protective factors are not inherently protective; rather, they are designated as such based on how they function in specific contexts. For example, higher IQ is usually related to positive outcomes in the broader resilience literature. In contrast, a landmark longitudinal study of individuals with FASD found that lower IQ was a protective factor (Streissguth et al., 2004). In this case, lower IQ was speculated to function protectively because of how this individual factor interacted with the environment: children with lower IQ were more likely to receive supports and services to address difficulties. Individuals with more severe forms of FASD and lower IQ may also experience different expectations for competency, as well as increased supervision into adulthood, potentially attenuating the opportunity to engage in risk behaviour.

Determining resilience involves making judgments about competent development. Individuals with complex developmental disabilities will, by definition, experience difficulty achieving typical levels of development across multiple domains of competence. These challenges are expected to persist across the lifespan. Therefore, the study of resilience in complex developmental disability populations requires a re-conceptualization of competence. Some have suggested that resilience should be re-framed as achievement of better-than-expected developmental outcomes (Climie et al., 2013; Gilmore et al., 2013). This would include consideration of typical clinical trajectories, challenges, and features of the specific condition being studied. Assessment of competence can then be established via within-group analysis based on typical clinical trajectories instead of normative standards. One illustration of this framework is optimal outcome research in ASD. Optimal outcome research focuses on establishing the parameters of developmental health in the context of a specific clinical disorder – that is, the extent to which an individual develops and changes to the point that their symptoms

fall below diagnostic thresholds (Fein et al., 2013; Szatmari et al., 2016). For example, Szatmari and colleagues (2016) proposed that resilient development among youth with ASD is characterized by positive functioning in five main domains: socialization (e.g., positive peer and family relationships, full community participation); functional independence (e.g., competence in activities of daily living, safe community functioning); self-determination (e.g., setting goals, problem-solving, making positive choices); educational achievement (e.g., participation, connection to school, academic achievement); and emotional/behavioural regulation (e.g., low frequency of behavioural problems).

Part Two: Thriving in Development

In psychology, thriving has been studied primarily within the context of positive youth development (PYD; e.g., Benson et al., 2006; Lerner et al., 2015) and positive psychology (Seligman & Csikszentmihalyi, 2000). There is little consensus on the specifics of thriving both within and between these fields; however, there is broad commonality. In general, thriving implies an energized process toward optimal human functioning and self-actualization.

Positive Youth Development and Thriving

PYD focuses on thriving in adolescence, and, like resilience, is theoretically rooted in relational-developmental systems theory. The PYD framework posits that all youth possess individual and ecological strengths (Benson & Scales, 2009). Youth development is dependent on a bidirectional interaction between the youth's individual qualities and their developmental contexts (Benson & Scales, 2009; Benson et al., 2006). The focus is on optimal human functioning and maximizing personal well-being and growth, rather than emphasizing competent development and the absence of problems, which is the focus of resilience.

From a PYD standpoint, thriving is defined as a dynamic process where a young person's individual qualities (e.g., competence, connection, character) grow and move the individual toward a form of self-actualization or "idealized personhood" characterized by the deployment of socially-valued behaviours such as contribution to self, family, community, and society (Benson & Scales, 2009). Thriving results from an individual's strengths or "specialness" being nurtured by the interaction between the individual and developmental contexts (e.g., people, places) that "know, affirm, celebrate, encourage, and guide" the expression of the individual's strengths (Benson & Scales, 2009, p. 90). Thriving reflects a mutual interaction between youth and their contexts: when young people are thriving, they are not just functioning optimally as individuals; they are also connecting with, contributing to, and bettering their relationships and communities.

Referring to a youth as thriving typically reflects where they are currently in their developmental journey to "idealized personhood." That is, thriving is not just about the attainment of exemplary development, but being on a path toward thriving. Most research has focused on describing individual characteristics (*thriving indicators)* of youth, as well as qualities of their environments (*developmental contexts)* that support thriving, discussed next.

Thriving Indicators

Over the past two decades, researchers have discussed, named, and measured indicators of thriving – that is, the "signs in early, mid, and late adolescence that a young person is moving toward (or is on a pathway to) a hopeful future in young adulthood and beyond" (Benson & Scales, 2009, p. 90). There is some overlap between thriving indicators proposed in different studies, but no consensus.

According to several PYD scholars, thriving-oriented youth typically manifest the 5Cs: *competence, confidence, character, connection*, and *caring* (Lerner et al., 2003; Lerner et al.,

2005; Roth & Brooks-Gunn, 2003a, 2003b). The longitudinal work of Lerner, Lerner and colleagues (the 4-H study of Positive Youth Development; e.g., Lerner et al., 2005) has examined the individual and ecological assets that form the building blocks of thriving in over 7000 adolescents from across the United States. The authors theorize that the presence of the 5Cs results in the emergence of a 6th C: *contributions* to self, family, community, and civil society. The work of other PYD scholars has expanded indicators of thriving from the 6Cs to encompass other indicators such as personal growth and purpose, spirituality, positive emotions and life satisfaction, and prosociality (see Table 2.1). *Sparks* are a key indicator of thriving in the PYD literature, defined as "a passion for a self-identified interest or skill, or a capacity that metaphorically lights a fire in an adolescent's life, providing energy, joy, purpose, and direction" (Scales et al., 2011, p. 264).

Although there is little consensus regarding specific indicators of thriving, even within studies of thriving (e.g., King et al., 2005), all extant studies share similarities. First, these inquiries are borne out of a spirit of studying strengths rather than pathology. Second, these studies are guided by PYD theory, which is influenced by relational-developmental systems theory, Maslow's theory of self-actualization, and understanding the role of ecology and context in the promotion of self (e.g., Bronfenbrenner, 1977). These lines of inquiry also acknowledge, at least implicitly, that thriving is not necessarily equivalent to happiness or that individuals who experience thriving are not living in contexts free of adversity or challenge. Third, these studies emphasize thriving as a process, reflecting growth and an upward trajectory borne out over time (Benson & Scales, 2009).

Table 2.1

Individual Indicators of Thriving from Key Studies

Category	Description	Thriving Indicators
Character and Positive Values	Sense of morality and integrity; respect for societal and cultural rules; values diversity	• Character[3, 4] • Moral compass[1-3] • Personal and Interpersonal Values[7] • Social conscience[7] • Values diversity and equity[1, 2, 5]
Competence	Positive view of one's actions in social, academic, cognitive, and vocational domains; ability to act effectively in different domains	• Self-regulation[3]; Intentional self-regulation[6] • School success[1,5]; Engagement[2, 7]; Connection[7] • Social, behavioural, academic competence[1]
Connection	Positive bonds with people, schools, communities; feeling of safety, structure, belonging	• Connection to Family; Community[7] • Connection[3, 4] • Activity participation[7]
Health and Safety	Maintains personal health and safety, follows rules, and resists negative influences	• Delays gratification[5] • Maintains Health[5] and Safety[7] • Positive health perception[1] • Rules and boundaries[2, 7] • Risk avoidance[7]
Growth and Purpose	Sense of purpose; wants to make a positive difference; sets goals and takes initiative	• Fulfillment of potential[1] • Personal growth[1] • Purpose[1] • Hopeful future[1, 6]
Positive Identity	Sense of self-worth and self-esteem; confident about capacity to succeed; positive view of personal future	• Confidence[3, 4] • Future-oriented[2] • Path to hopeful future[2] • Positive identity[7] • Personal power[1] • Search for positive identity[2]
Prosocial Orientation	Showing empathy and care for others	• Caring[3, 4] • Prosocial orientation[1, 6] • Helps others[5]
Sparks	Identifying and pursuing talents and interests that confer energy and purpose	• Motivation (to pursue sparks intrinsically)[1] • Spark identification[1] • Stability/growth of spark[1]
Spiritual Development	Embraces importance of a transcendent force; faith or spirituality helps shape everyday thoughts and actions	• Spiritual engagement[5] • Spiritual identity[1] • Transcendent awareness[6]
Well-Being	Feels positive emotions, optimism, and life satisfaction	• Positive emotions[3] • Positive emotionality[1, 6] • Life satisfaction[1]

[1]Benson & Scales (2009); [2]Dowling et al. (2003); [3]King et al. (2005); [4]Lerner et al. (2005); [5]Scales et al. (2000); [6]Search Institute (2014); [7]Theokas et al. (2005).

Developmental Contexts Associated with Thriving

Developmental contexts include the people and places that act on the youth to nurture their development (Arnold, 2018; Benson & Scales, 2009). Typically, these include: family, peers, schools, neighborhoods, and community organizations. Each of these contexts can provide key ingredients that help nurture thriving. One critical element that developmental contexts can provide is a venue to develop *positive relationships* with adults. Positive relationships that support thriving have three main qualities (Arnold, 2018; Bowers et al., 2015). First, there is *secure attachment* between youth and key adults, characterized by warmth, trust, and respect. Second, there is the experience of *mutuality* in youth-adult relationships. Third, youth-adult relationships are characterized by *flexibility and change*: as youth grow, the balance of guidance and power provided by adults shifts to reflect the youth's growing autonomy. Additional elements of developmental contexts that support thriving include *opportunities* (i.e., youth have the chance to grow and develop their strengths), *support* (i.e., receiving encouragement and support to pursue strengths), *boundaries and expectations* (i.e., positive pressure to pursue goals and talents), and *constructive use of time* (Benson & Scales, 2009).

Positive Psychology and Thriving

Positive psychology is a broad field that focuses on multiple aspects of encouraging the growth of mental health and well-being (Hart & Sasso, 2011; Seligman & Csikszentmihalyi, 2000). The positive psychology field has examined several constructs that share conceptual space with the PYD construct of thriving, including *flourishing*, *well-being*, *character strengths and virtues,* and *thriving at work*. These have been primarily investigated among adults.

Flourishing

Flourishing is described as the "optimal range of human functioning" that "connotes goodness, generativity, growth, and resilience" (Fredrickson & Losada, 2005, p. 678) and the state of being "filled with positive emotions" (Keyes, 2002, p. 2010). Positivity and positive affect are the central indicators of flourishing. Supporting elements include personal growth (Keyes, 2007), life satisfaction, hope, generosity, spirituality, connectedness, self-regulation, and prosocial orientation (Moore & Lippman, 2005).

Subjective Well-Being

Subjective well-being (SWB) is concerned with an individual's life satisfaction and emotional experiences (Diener et al., 2009). High SWB is characterized by having high life satisfaction, frequent positive emotions, and infrequent negative emotions. SWB is typically discussed from two related perspectives: hedonic well-being, and eudaimonic well-being (Ryan & Deci, 2001). Hedonic well-being focuses on individual experiences of happiness, pleasure, and enjoyment of life. Eudaimonic (or psychological) well-being focuses on deeper individual needs such as those for meaning, purpose, and actualization of potential. Ryff's (2014) six-component model of psychological well-being proposes that experiencing environmental mastery, personal growth, self-acceptance, life purpose, connections with others, and autonomy are connected to high well-being.

Character Strengths and Virtues

Peterson and Seligman (2004) proposed that there are 24 character strengths that can be organized into six universal virtues: *wisdom, courage, humanity, justice, temperance*, and *transcendence*. Character strengths (e.g., creativity, perseverance, love, leadership, self-regulation, hope) are different from talents, interests, and skills. Rather, they are defined as positive traits that are expressed through thinking, feeling, and behaving in ways that benefit the

self and others. These positive characteristics are believed to potentiate human flourishing and SWB (Niemiec, 2013). For example, research has consistently documented a strong relationship between life satisfaction and the character strengths of hope, zest, gratitude, curiosity, and love.

Thriving at Work

Spreitzer and colleagues (2005) proposed that individuals who are thriving in the workplace demonstrate a combined sense of vitality and learning. Vitality is similar to well-being, reflecting a positive emotional state and energy. Learning refers to the process of gaining knowledge and advancing at work. Spreitzer and colleagues also highlight the role of contextual factors in supporting thriving at work, such as a healthy and positive work environment, as well as subjective experiences including feeling a sense of belonging and connection. Spreitzer and Porath (2013) described an integrated model of thriving, which combines thriving at work with self-determination theory (SDT; e.g., Deci & Ryan, 2000). SDT asserts that human growth is driven by the need to satisfy three psychological needs: autonomy, competence, and relatedness. In this integrated model, these needs provide the "nutriments" for thriving, and vitality and learning are the indicators that thriving is occurring.

Rationale for Studying Thriving

Clearly, the positive psychology constructs of flourishing, subjective well-being, character strengths, and thriving at work share considerable conceptual overlap with the construct of thriving informed by PYD and relational-developmental systems theory. Yet, there are important differences. I have elected to use the latter framework to examine thriving or optimal functioning among young people with FASD and developmental disabilities for two main reasons. First, the PYD-informed construct of thriving is specific to the developmental periods of adolescence and emerging adulthood, whereas positive psychology constructs tend to

focus on adults. Second, because of the grounding in relational-developmental systems theory, PYD's concept of thriving focuses much more on dynamic processes of growth, development, and the interaction between individual and context compared to positive psychology constructs. This aligns well with the prevailing social-ecological model of disability that suggests that individuals with disabilities develop best when their unique individual characteristics are adequately supported by their environment (e.g., Buntinx, 2013; Schalock et al., 2010). Using a framework that encourages the study of individual qualities associated with thriving, the relational and contextual factors that support individuals to thrive, and the interaction between these systems, may ultimately be more useful than frameworks that focus solely on individual characteristics. This is because intervention in developmental populations typically focuses on supporting individuals directly and systemically, with the acknowledgement that youth with and without disabilities are affected significantly by context.

Issues in the Thriving Literature

Several problems remain in trying to integrate the thriving literature into a coherent set of indicators. First, although most researchers seem to agree that thriving is a dynamic process, thriving indicators are framed inconsistently as processes, outcomes, or a combination of both. Second, there is little agreement as to whether thriving is a global or domain-specific construct. For example, can an individual demonstrate thriving in one context (e.g., school) but not another (e.g., work)? How many domains/indicators of thriving must a person fulfill to be considered thriving? Should breadth of thriving (e.g., a total score) be sufficient, or does the pattern across different domains matter? Third, some have argued that thriving is a culturally and socioeconomically privileged construct. (Benson & Scales, 2009; Sesma et al., 2013). Some markers of thriving (e.g., leadership, scholastic achievement, championing individualistic

pursuits) may not be valued in all cultures or groups. In addition, thriving should theoretically be independent of social class; yet, thriving may present differently among different groups. For example, the thriving indicator of "using one's talents to contribute to society" is sometimes operationalized by identifying the frequency of volunteering, an activity which tends to be more common among Caucasian youth and those from higher socioeconomic brackets (Spring et al., 2008). Finally, explorations of thriving in development has generally been restricted to typically developing populations.

Thriving With a Developmental Disability

According to King and colleagues (2005), the concept of thriving doesn't negate the possibility that youth with non-normative developmental experiences or capacities – such as those exposed to significant adversity or those with developmental disabilities – can "flourish in comparison with others of their ability status" and "show appreciable gains across adolescence in his or her psychological or behavioural functioning" (King et al., 2005, p. 96). Yet, few have examined what it means to thrive as an individual with a developmental disability, and there have been no studies examining thriving with FASD to date.

Weiss and Riosa (2015) published the first direct examination of thriving among youth with complex developmental disabilities. They administered a six-question quantitative survey of the 6Cs of positive youth development to parents of 330 youth aged 11 to 22 with ID and ASD. Youth with dual diagnoses of ASD and ID were reported to thrive less than their peers with ID. The relationship between poorer thriving and an ASD diagnosis was mediated by socio-communicative ability and school participation. While this provided an important first step, there were several limitations to this study. First, only the perspectives of parents were elicited. Thus, answers only reflected caregiver's perspectives on whether youth met certain observable criteria,

and not youth's subjective experience of thriving. Second, the measure of thriving employed was based on qualities and outcomes established in typically developing youth, many of whom were exceeding developmental expectations. Problematically, this assumes that youth with ASD and ID thrive in the same way as their typically developing peers. It is not unreasonable to expect that the qualities that comprise thriving may differ in populations in which development is non-normative. For example, the question about *competence* was, "My child has the skills to succeed in school, in social situations, with friends and adults, with play, and at home. My child knows how to behave and does what is needed to do well" (p. 2479). What does it mean for a child with ASD and ID to "succeed in school," "behave," or "do well?" Is this in relation to other children without cognitive differences? In relation to other children with ASD and ID? Or is it in comparison to an individual youth's perceived potential, or how they used to do in the past? Are competence and the other 5Cs valued or seen as indicative of thriving by individuals with ASD and ID, or their families and communities? The authors reported that individuals with ASD and ID thrived "less" than peers with ID only – is it possible that participants with ASD and ID just thrive differently? I believe the critical next question is *not* how much individuals with developmental disabilities thrive in relation to others, but rather what thriving with a specific disability looks like, how it is understood by people living the experience, how the process of thriving unfolds developmentally within individuals with developmental disabilities, and how thriving can be supported.

Addressing some of these concerns, a recent doctoral dissertation examined thriving among young adults with ID and Down's syndrome. Thompson (2018) proposed that thriving with ID occurs when individuals report high subjective well-being, positive transactional relationships between individuals and their support systems, and developmental growth. Using a

qualitative multiple case study design, Thompson found that factors that facilitated thriving with Down's syndrome and ID included supportive social systems, creating family, having high expectations for independence, caregiver advocacy, focusing on physical well-being, and assessing strengths. There is clearly some overlap between these factors and those described in the broader thriving literature, but also some unique factors specific to this population (e.g., strengths-based assessment) that may be relevant to other developmental disability populations.

Summary

The constructs of resilience and thriving provide insight into how typically developing children and youth are able to engage in positive developmental trajectories. Substantially less is known about these processes in young people with complex developmental disabilities like FASD.

In terms of resilience, many of the same protective processes that allow for competent development in typically developing youth exposed to significant adversity may help youth with developmental disabilities develop healthily too. For example, caring and supportive relationships and positive school ecologies appear to be helpful to all youth, regardless of background. However, there is evidence in the literature to suggest that some individual and environmental protective factors may function differently in populations with developmental disabilities – for example, severity of cognitive impairment may interact with the environment to confer protection against negative outcomes by permitting access to services. There may also be certain protective factors that are more specific to having a disability, such as the importance of integrating disability into one's identity, or caregiver advocacy. Further, studying resilience in populations with developmental disabilities requires considering how to define competent development for specific clinical conditions. Future research in specific developmental disability

populations should consider framing resilience as “better-than-expected” development based on typical clinical trajectories for specific conditions rather than on normative standards. Further, qualitative or quantitative examinations of individual and environmental protective factors that may be specific to the experience of disability would be helpful.

Thriving is concerned with optimal development and functioning. It is a construct that has been studied almost exclusively within typically developing youth. It is possible that youth with developmental disabilities thrive in similar ways to those without disabilities. However, it is just as likely that the experience of disability and the ways in which disability interacts with the environment may change the ways individuals with disabilities thrive. While PYD provides a useful starting point, investigations of thriving in specific populations with developmental disabilities may benefit from beginning inductively, seeking to understand what it means to thrive with a specific developmental disability rather than in comparison to normative expectations.

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Chapter 3: Resilience Resources and Emotional and Behavioural Functioning Among Youth and Young Adults With Fetal Alcohol Spectrum Disorder

Fetal Alcohol Spectrum Disorder (FASD) is a neurodevelopmental disorder that results from alcohol exposure during pregnancy. Individuals with FASD present with numerous challenges, which typically include a range of mild to severe impairment in executive functioning, intellectual ability, learning, academic achievement, memory, attention, language, and adaptive functioning (for a review, see Mattson et al., 2019). Furthermore, individuals with FASD appear to be at greater risk of being exposed to abuse, neglect, and domestic violence; being raised in a non-biological home or by a single parent; experiencing multiple living arrangements; being raised in a low-income household; and having parents with substance abuse or mental health problems (Kambeitz et al., 2019; McLachlan et al., 2015; Streissguth et al., 2004). This frequent co-occurrence of neurodevelopmental disability and environmental adversity has led some to describe FASD as a disorder of "double jeopardy" (Coggins et al., 2007). The interaction between these two broad categories of vulnerability may contribute to the host of poor outcomes associated with FASD, including educational disruption (e.g., academic failure, major behavioural issues, suspension, expulsion), challenges with employment and independent living, justice involvement, substance abuse (Clark et al., 2004; McLachlan et al., 2020; Streissguth et al., 2004) and neurodevelopmental co-morbidity (Kambeitz et al., 2019). Mental health comorbidity is also common, with up to 90% of clinically-referred individuals with FASD reporting at least one concurrent mental health diagnosis (Pei et al., 2011).

The literature tends to focus on the risks and adverse outcomes associated with FASD. Yet, despite the (often) double-barreled challenges individuals with FASD face, not everyone experiences negative outcomes. Indeed, there is substantial heterogeneity in clinical presentation (e.g., Nash et al., 2013; Quattlebaum & O'Connor, 2012) and outcomes for individuals with

FASD (e.g., Lynch et al., 2015; Rangmar et al., 2015; Streissguth, 2007). For example, two recent studies of outcome trajectories reported that the majority of adults with FASD lag significantly behind their peers in achieving independence and educational milestones (Lynch et al., 2015; Rangmar et al., 2015). However, just under 50% of adults with FASD in these studies were employed. Further, Lynch and colleagues (2015) reported that up to 48.6% of adults with FASD in their sample were living independently, up to 62.2% of adults were high school graduates, and as many as 48.9% had pursued some form of post-secondary education. This significant variability in trajectories suggests that some form of *resilience* process may operate within this population.

Resilience

Resilience is a phenomenon defined by competent (or developmentally typical) adaptation amidst adversity (Masten & Cicchetti, 2016). Adversity is frequently conceptualized as exposure to environmental risk factors, such as trauma (e.g., abuse, neglect, exposure to violence, natural disaster, war), poverty, or parental mental illness. Exposure to multiple risk factors tends to be associated with poorer developmental outcomes (Evans et al., 2013; Obradović et al., 2012), and may be inversely related to the availability of protective resources that help attenuate the negative impact of risk (e.g., Bellis et al., 2018). The majority of resilience research has focused on individuals who are otherwise developing normally, but have experienced significant environmental adversity. There is a dearth of research examining resilience among young people with complex developmental disabilities like FASD. Some have argued that the traditional definition of resilience (i.e., developing normally after adversity) has hindered the study of resilience in populations with developmental disabilities (Gilmore et al., 2013). A more inclusive definition emphasizes *better-than-anticipated* functioning, understood within the context of

typical clinical outcomes and an individual's own development, clinical presentation, and environment (Climie et al., 2013; Gilmore et al., 2013; Ungar, 2015).

Resilience is typically conceptualized as a developmental process: in the course of development, *individual* (or internal) resources such as personality traits and skills and *environmental* (or external) resources such as *relational* (e.g., supportive relationships) and *contextual* (e.g., community, culture, and school connectedness) assets interact to mitigate the impact of risk and help individuals navigate toward healthier outcomes (Masten & Cicchetti, 2016; Ungar, 2011). By virtue of characteristic brain-based deficits, conditions like FASD inherently challenge typical individual resilience-building resources such as social competence, self-regulation, and autonomy. The neurodevelopmental challenges associated with FASD can also impact environmental sources of resilience such as relationships with family and school, either via individual mechanisms (e.g., attachment difficulties) or through broader systemic forces (e.g., the stress that disability places on families/within schools disrupts the development of supportive relationships). Understanding the individual and environmental protective resources operating in specific populations like FASD is critical to supporting resilient trajectories. Although findings from otherwise typically developing populations provide a starting point, resilience resources may operate differently in the context of developmental disability.

Resilience and FASD

The first studies of resilience in FASD reflected a lens that focused on identifying factors that helped individuals with FASD *avoid* poor outcomes. In a landmark longitudinal study of 415 individuals with FASD, Streissguth and colleagues (2004) found that several protective factors were related to lower rates of negative life outcomes (e.g., school disruption, lack of employment, inability to live independently, incarceration). These protective factors included living in a stable home environment, not being exposed to violence, receiving services, and being diagnosed before

age six. The individual qualities of low IQ and higher diagnostic severity (i.e., poorer cognitive functioning) were also found to be protective, which is the opposite of what is usually found in the broader resilience literature (Masten & Cicchetti, 2016). The authors speculated that these individual characteristics helped individuals gain access to supportive external resources (e.g., services), illustrating an interaction between individual and environmental protective factors. However, a recent Canada-wide retrospective cross-sectional analysis of risk factors and "difficulties in daily living" (e.g., challenges with education, occupation, independent living, substance use, criminal offending, victimization) among 726 adolescents and adults with prenatal alcohol exposure and FASD found that lower IQ and increased diagnostic severity was related to greater cumulative difficulties (McLachlan et al., 2020). McLachlan and colleagues (2020) also found that postnatal trauma and older age were associated with greater cumulative difficulties. Gender did not predict cumulative difficulty; however, significantly more males reported school disruption and criminal offending, and more females reported incarceration.

Qualitative investigations of resilience among youth with FASD have focused on exploring factors that promote positive development rather than on those that help avoid negative outcomes. Relational supports – such as caring and supportive relationships with caregivers, peers, teachers, and community members – have been consistently found to support elements of positive trajectories (Knorr & McIntyre, 2016) such as school persistence (Duquette & Stodel, 2005; Duquette et al., 2006), and successful transition from the child welfare system to adulthood (Burnside & Fuchs, 2013). Caregiver advocacy has additionally been implicated as a strong relational resource that supports academic success (Duquette & Stodel, 2005; Duquette et al., 2006). Individual qualities such as self-perception of strengths (Duquette et al., 2006) and awareness of challenges (Brenna et al., 2017) and contextual resources such as individually-appropriate and collaborative educational supports and programming (Duquette & Stodel, 2005;

Duquette et al., 2006; Job et al., 2013; Millar et al., 2017), involvement in school activities, or attendance at youth programs and community centers (Knorr & McIntyre, 2016) have also been reported as resilience-building. These different types of resilience resources appear to interact to support positive trajectories. For example, Duquette and colleagues (2006) found that self-perception of academic and social success (despite limited academic performance and peer connection) was connected to a greater sense of belonging and integration at school; together, participants described these assets as supportive of school persistence.

Rogers and colleagues (2013) provided the first quantitative measurement of resilience resources among individuals with FASD by using a self-report measure of individual, relational, and contextual resilience resources (the Child and Youth Resilience Measure; CYRM) with 94 young offenders aged 13 to 23 years, half of whom had FASD. The authors found that youth with FASD reported similar levels of resilience resources as their non-affected peers. They also found that levels of resilience resources were positively related to enculturation and inversely related to self-reported offending. A diagnosis of FASD did not moderate the relationship between resilience resources and rates of past offending, suggesting young offenders with and without FASD demonstrated a similar relationship between resilience resources and offending.

The extant research has shown that some individual, relational, and contextual resources support positive trajectories among youth with FASD, particularly outcomes related to education. However, more research is needed to provide a more detailed profile of resilience resources and how these resources relate to other aspects of healthy development that are particularly salient to individuals with FASD, such as emotional and behavioural functioning. In addition, understanding how exposure to early childhood adversity, potential protective experiences, and individual characteristics relate to resilience resources would be valuable.

Purpose and Research Questions

The purpose of this study was to describe the profile of resilience resources reported by youth with FASD and their caregivers and how these resources relate to early adversity and potential protective factors as well as concurrently reported emotional and behavioural functioning. Given the limited research in this area, I used an exploratory approach and cross-sectional design to answer the following research questions:

Profile of Resilience Resources

1a. What level of resilience resources do youth with FASD and their caregivers report on the Child and Youth Resilience Measure (CYRM)?

I anticipated that youth with FASD would report significantly more resilience resources than their caregivers. This hypothesis was based on prior documentation of differences between parent and adolescent reporting on the CYRM (Sanders et al., 2013) as well as a larger base of research suggesting a lack of concordance between youth self-report and caregiver report of emotional and behavioural functioning (e.g., Achenbach et al., 1987; van der Ende et al., 2012), including among youth with FASD (Mariasine et al., 2014). To contextualize the level of resilience resources reported by participants, I compared their scores to the two CYRM normative sample groups: low-risk youth and complex-needs youth. I expected that youth with FASD would report similar levels of resilience resources as low-risk youth (Rogers et al., 2013) and that caregivers would report similar levels to complex-needs youth (Sanders et al., 2013).

1b. Are resilience resources differentially allocated between specific domains of resilience (individual, relational, contextual)?

Based on profiles of resilience resources in the CYRM normative sample and other clinical samples (e.g., Rogers et al., 2013), I hypothesized that youth with FASD and their caregivers would both report fewest contextual resources. I also anticipated that youth with

FASD would report the most individual resources, and that caregivers would report the highest level of relational resources.

Association Between Resilience Resources and Other Factors

2a. How does early childhood adversity relate to resilience resources among youth with FASD?

Based on general population-based research (e.g., Bellis et al., 2018), I expected that greater exposure to early adversity would be inversely related to levels of resilience resources.

2b. How do the potential protective experiences of early stability and diagnosis relate to resilience resources among youth with FASD?

Among individuals with FASD, stability of living arrangement and earlier age of diagnosis have been associated with lower rates of adverse outcomes (e.g., Streissguth et al., 2004), but the connection between these factors and resilience resources has not been studied; therefore, this question is exploratory.

2c. How do the potential individual protective factors of age, sex, and IQ relate to resilience resources among youth with FASD?

This question is exploratory. Among individuals with FASD, the relationship between gender, IQ, and adverse outcomes has been mixed (McLachlan et al., 2020; Streissguth et al., 2004). In one study, older age was associated with greater cumulative difficulties (McLachlan et al., 2020). However, the connection between these variables and resilience resources has not been studied.

Resilience Resources and Emotional and Behavioural Functioning

3. What is the association between resilience resources and concurrently reported emotional and behavioural functioning, including when exposure to early childhood adversity is considered?

Based on previous research among adolescents with complex needs (Afifi & MacMillan, 2011; Hains et al., 2014; LaFromboise et al., 2006), I hypothesized that higher individual, relational, and contextual resilience resources on the CYRM would be associated with fewer emotional and behavioural symptoms and significantly better adaptive functioning, even when exposure to adversity is controlled.

Method

Participants

Nineteen clinically-referred youth and young adults with FASD (henceforth referred to as "youth with FASD") and their caregivers agreed to participate. Youth were 13 to 23 years old (*M* = 17.8 years); 47.4% identified as female and 52.6% identified as male (Table 3.1). All youth had been previously diagnosed with FASD by a multidisciplinary diagnostic team following the Canadian guidelines for FASD diagnosis (Chudley et al., 2005; Cook et al., 2016). All caregivers identified as female, and were either adoptive (63.2%) or long-term foster parents (36.8%) still actively involved in youth's lives. The majority of youth participants (*n* = 16) and their caregivers were recruited via convenience sampling through a larger study of patients assessed at an urban FASD diagnostic clinic. The remaining three participants were recruited through a rural FASD mentorship program. An institutional ethical review board approved the study. All participants older than 18 years provided informed consent. Youth under age 18 provided assent, while their caregivers gave informed consent.

Measures

Demographic Questionnaire

Caregivers completed a brief questionnaire regarding the youth's age, placement history, and current living situation, and caregiver factors such as relationship to the youth.

Table 3.1

Participant Characteristics

Demographic Variable	
Sex – % Female (*n*)	47.4 (9)
Current Age – *M* years (range) Adolescent (13-17 years) – % (*n*) Young Adult (18-23 years) – % (*n*)	17.8 (12-23) 57.9 (11) 42.1 (8)
Age at FASD Diagnosis – *M* years (Range)	7.4 (1-14)
Full-Scale IQ – *M* Standard Score (Range)	88 (70 – 102)
Ethnicity – % (*n*) Caucasian First Nations and Métis	 36.8 (7) 63.2 (12)
Caregiver Relationship to Youth – % (*n*) Adoptive Parent Foster Parent Kinship Foster Parent	 63.2 (12) 31.6 (6) 5.2 (1)
Length of Youth-Caregiver Relationship – *M* years (range)	14.5 (9-21)
Age Entered Stable Placement – *M* years (range) Before Age 2 – % (*n*)	3.0 (birth-12) 52.6 (10)

Adverse Childhood Experiences Questionnaire

Assessing resilience requires establishing risk. Although participants could already be considered at-risk due to their FASD diagnosis, it was important to also account for environmental risk. The Adverse Childhood Experiences (ACE) score (e.g., Dube et al., 2003) is a common metric of risk. The present study considered ACEs from three main areas. *Abuse* encompasses: *psychological abuse* (i.e., child subjected to swearing, insults, humiliation, threats), *physical abuse* (i.e., child pushed, slapped, grabbed, had things thrown at them, or injured by caregiver), and *sexual abuse* (i.e., child sexually touched by person at least five years older). *Neglect* is a single area that addresses physical or emotional neglect (i.e., child's basic needs unmet, child left unsupervised, child felt unloved or unsupported by caregivers). Finally, *Household dysfunction* encompasses five areas: *exposure to substance abuse*, *exposure to serious*

mental illness, exposure to domestic violence, *incarceration of household member,* and *parental separation/divorce*. Using answers caregivers provided, participants were defined as exposed to a category if they endorsed one or more of the questions in each category. The total number of endorsements were summed to yield a total ACE score, ranging from 0 to 9.

Child and Youth Resilience Measure (CYRM)

Youth and caregivers completed the CYRM-28 (Ungar, 2013a), a 28-item (5-point Likert scale) questionnaire that assesses three key types of resilience resources among youth aged 9 to 23 years: individual (personal skills, peer support, social skills), relational (physical and psychological caregiving), and contextual (spiritual, educational, and cultural). Items on the Youth Self-Report and Caregiver Report are directly comparable. Answers are summed to yield a total score, as well as scores for each domain and subdomain. Higher scores represent more resilience resources. Because each domain and subscale contain different numbers of items and because standardized scores are not available, the resulting scores are difficult to compare across the resilience resource profile. To permit comparison, all scores were converted to out of 100 (Sanders et al., 2013). The CYRM manual provides mean scores for two normative groups to anchor comparisons: 1) low-risk (typical Canadian) youth; and 2) "complex-needs" youth (those involved with two or more mandated services; e.g., mental health, justice).

The CYRM has acceptable internal consistency; Cronbach's alpha in the present study was .90 and .94 for youth and caregiver reports respectively. There is also strong evidence of construct validity and content validity. The manual does not include published data regarding criterion-related validity, but other studies have demonstrated significant correlations in the expected directions between CYRM scores and outcomes such as concurrent mental health diagnoses (Broderson, 2013; Hains et al., 2014). Although not designed specifically for use with individuals with FASD, the CYRM may be a good fit for this population due to overlap between

individuals with FASD and other complex groups that form the basis of the CYRM development and normative samples (e.g., youth accessing social, mental health, or justice services).

Behaviour Assessment System for Children – Second Edition (BASC-2)

The BASC-2 questionnaire (Reynolds & Kamphaus, 2006) is widely used to assess emotional and behavioural functioning among children and youth. Youth aged 13 to 21 years completed the Adolescent Self-Report; those older than 21 years (n = 4) completed the College Self-Report. Caregivers of youth aged 13 to 21 years (n = 16) completed the BASC-2 Parent Report. Both Youth and Parent Report forms yield different composites, reflecting differences in item content and phrasing. The Youth Report yields four Clinical composites and one Adaptive Skills composite: School Problems (*Attitude to School, Attitude to Teachers, Sensation Seeking*; Adolescent Form only*)*, Internalizing Problems (*Atypicality, Locus of Control, Social Stress, Anxiety, Depression, Sense of Inadequacy, Somatization*), Inattention/Hyperactivity (*Attention Problems, Hyperactivity)*, Emotional Symptoms Index (*Social Stress, Anxiety, Depression, Sense of Inadequacy, Self-Esteem, Self-Reliance*), and Personal Adjustment (*Relations with Parents, Interpersonal Relations, Self-Esteem, Self-Reliance)*. The Parent Report results in three clinical composites and one adaptive composite: Externalizing Problems (*Hyperactivity, Aggression, Conduct Problems),* Internalizing Problems (*Anxiety, Depression, Somatization),* Behavioural Symptoms Index (*Hyperactivity, Aggression, Depression, Atypicality, Withdrawal, Attention Problems),* and Adaptive Skills (*Adaptability, Social Skills, Leadership, Activities of Daily Living, Functional Communication).* Scores are reported as age-normed t-scores (M = 50, SD = 10). T-scores between 60 – 69 on Clinical scales and 31 – 40 on Adaptive scales fall in the *at-risk* range, while scores 70 and above on the Clinical scales and 30 and below on Adaptive scales are considered *clinically significant*. Both Youth and Parent forms of the BASC-2 have high internal

consistency (.90 - .95 for composites and .83 - .87 for individual subscales) and good validity as they correlate highly with other symptom-based measures of mental health and behaviour.

Wide Range Intelligence Test (WRIT)

Sixteen youth completed the WRIT (Glutting et al., 2000), a brief and reliable measure of general cognitive ability among individuals aged 4 to 85 years. The WRIT Full-Scale IQ (FSIQ) score reflects verbal (crystallized) and visual (fluid) abilities. Scores are reported as standard scores (M = 100, SD = 15).

Procedure

Youth and caregivers completed questionnaires separately. All questionnaires were paper-and-pencil based, with the exception of the CYRM-28 which was administered on a computer. The lead author or a research assistant provided visual supports to aid interpretation of Likert-type and forced choice responses, as well as reading assistance as requested to participants with reading difficulties.

Data Analysis

To assess the profile of resilience resources reported by youth with FASD and their caregivers, CYRM responses were contextualized by comparing average reported scores on the three CYRM composites (individual, relational, contextual) and the CYRM total score to the normative mean scores of the two CYRM normative groups with one-sample *t*-tests. Next, I performed a 2 (group) x 3 (composite) mixed-design ANOVA to compare youth and caregiver responses across the three main CYRM composites, as well as to determine how composite scores compared within groups. I conducted a separate one-way ANOVA to examine the difference between youth and caregiver total CYRM score. I used descriptive statistics to calculate average scores within separate subscales to provide more detail about the distribution of specific resilience resources. I then examined the association between early experiences and

resilience resources and individual characteristics and resilience resources using Pearson correlations for continuous variables (i.e., ACE score, age, IQ) and Point Biserial correlations for dichotomous variables (i.e., sex). Finally, to assess the relationship between resilience resources and emotional and behavioural functioning, I performed Pearson correlations between the BASC-2 and CYRM-28 composites for youth and caregivers separately. Partial correlation analyses were then used to assess the relationship between these variables partialling out early childhood adversity (ACE score). An alpha level of .05 was used for all statistical tests due to the exploratory nature of this study and the small sample size.

Results

Profile of Resilience Resources

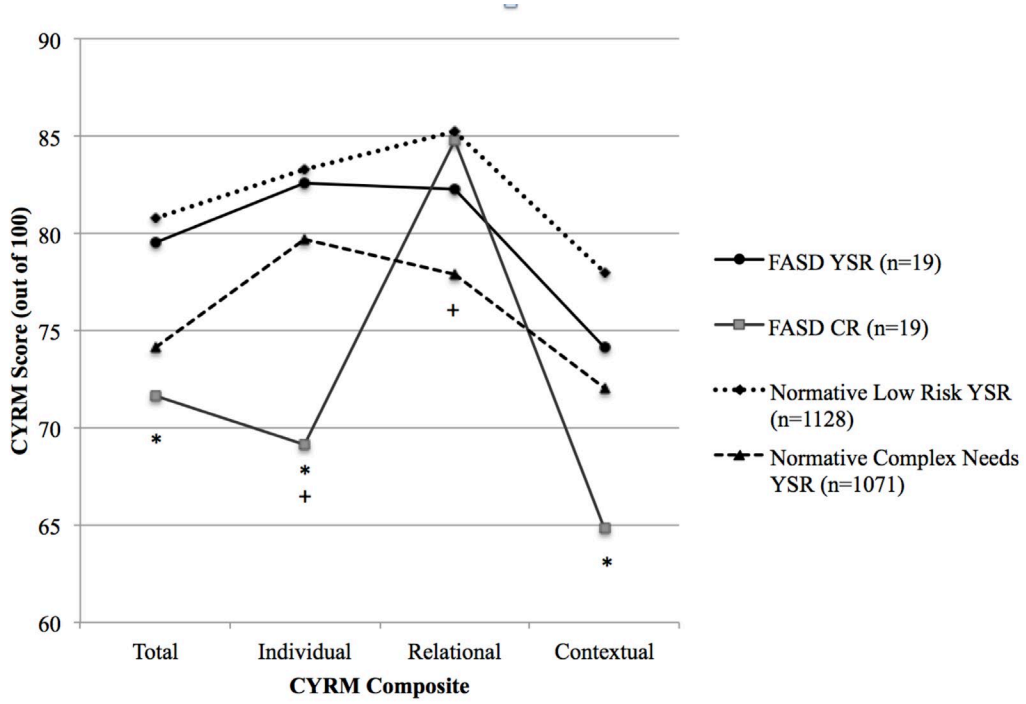
Overall, youth with FASD reported relatively high total, individual, relational, and contextual resilience resources, with mean scores comparable to low-risk youth in the CYRM normative sample, *p*s > .05 (Figure 3.1). In contrast, caregivers reported that youth with FASD had significantly fewer total and contextual resilience resources compared to low-risk youth, $t(18) = -3.39$, $p = .003$; $t(18) = -3.09$, $p = .006$ respectively. Furthermore, caregivers reported that youth with FASD had significantly fewer individual resources than both low-risk youth, $t(18) = -4.71$, $p < .001$, and complex-needs youth, $t(18) = -3.51$, $p = .002$ from the normative sample. However, caregivers reported that youth with FASD possessed significantly greater relational resources than complex-needs youth, $t(18) = 2.69$, $p = .02$, with scores comparable to low-risk youth.

Youth with FASD reported significantly more total resilience resources compared to caregivers (see Table 3.2). Comparing scores across the three composites (individual, relational, contextual), a 2 (group) x 3 (composite) mixed-design ANOVA showed a significant main effect for composite, $F(2, 72) = 28.84$, $p < .001$, $\eta^2_P = .45$, indicating that overall score differed across

composites. Together, mean scores were highest for relational resources (*M* = 83.53*)* followed by individual resources (*M* = 75.89) and contextual resources (*M* = 69.47).

Figure 3.1

Comparison of FASD Youth Self-Report and Caregiver CYRM-28 Scores to Normative Data



Note. YSR = Youth Self-Report; CR = Caregiver Report. All CYRM-28 scores converted to out of 100 (Sanders et al., 2013).

*$p < .01$ FASD CR vs. Normative Low-Risk YSR

+$p < .05$ FASD CR vs. Normative Complex Needs YSR

There was no significant main effect of group, F (1, 36) = 3.03, p = .09. However, there was a significant interaction between composite and group, F (2, 72) = 9.87, $p < .001$, $\eta^2_P = .22$).

I examined the source of this interaction in two ways. First, I examined the simple main effect of group by conducting three one-way ANOVAs to compare youth and caregiver scores across the three composites (Table 3.2). The interaction was due to youth with FASD reporting significantly

more individual resilience resources than caregivers, $F(1, 36) = 12.19$, $p = .001$, but similar levels of overall relational resources and contextual resources. Next, I examined the simple main effect of composite by conducting an additional repeated-measures ANOVA separately for each group. There was a significant effect of composite for both youth, $F(2, 36) = 7.69$, $p = .002$, $\eta^2_P = .30$, and caregivers, $F(2, 36) = 28.47$, $p < .001$, $\eta^2_P = .61$, indicating significant differences between two or more composites within each group. Post hoc pairwise comparisons using Bonferroni correction indicated that youth reported significantly more individual resources than contextual resources, $p = .009$, and significantly more relational resources than contextual resources, $p = .020$. Caregivers reported significantly more relational resources than individual and contextual resources, $p < .001$.

Table 3.2

Comparison of Youth and Caregiver Responses on the CYRM-28 and Subscales

	FASD Youth Self-Report *M* (*SD*)	**FASD Caregiver Report *M* (*SD*)**	***p*-value**	***η²***
Individual Resources	82.58 (10.43)	69.19 (13.08)	.001**	.25
Personal Skills	79.58 (10.91)	65.26 (14.73)		
Peer Support	82.60 (18.80)	65.26 (22.4)		
Social Skills	86.32 (12.23)	76.05 (11.96)		
Relational Resources	82.26 (11.80)	84.81 (11.19)	.498	.01
Physical Caregiving	84.21 (11.21)	87.37 (12.40)		
Psychological Caregiving	81.26 (13.86)	83.79 (14.27)		
Contextual Resources	74.12 (14.73)	64.84 (18.59)	.097	.08
Spiritual	61.73 (23.81)	51.58 (24.53)		
Education	83.16 (34.49)	62.11 (26.37)		
Cultural	77.47 (13.48)	73.89 (15.34)		
Total Resilience Resources	79.51 (10.85)	71.65 (13.18)	.048*	.10

Note. All CYRM-28 scores converted to out of 100 (Sanders et al., 2013). Post-hoc comparisons conducted via one-way ANOVA.

*$p < .05$; **$p < .01$

Association Between Resilience Resources and Other Factors

More than two-thirds of youth with FASD were reportedly exposed to at least one ACE, and over a quarter were exposed to four or more ACEs (see Table 3.3). The most commonly reported ACEs were childhood neglect and exposure to household substance abuse, both reportedly experienced by nearly half of youth participants. In addition, nearly one-third of youth were reportedly exposed to serious mental illness within their households and parental separation or divorce. Total ACE score was not significantly correlated with any of the CYRM composite scales (Table 3.4), although the association between ACE score and youth-reported individual resilience resources approached significance, $p = .06$.

Table 3.3

Sample Prevalence of Adverse Childhood Experiences (ACEs)

ACE Category	**Proportion (*n*)**
Childhood Abuse and Neglect	
1. *Psychological Abuse*	21.1% (4)
2. *Sexual Abuse*	10.5% (2)
3. *Physical Abuse*	10.5% (2)
4. Neglect	42.1% (8)
Household Dysfunction	
5. *Substance Use*	47.4% (9)
6. *Mental Illness*	31.6% (6)
7. *Domestic Violence*	10.5% (2)
8. *Incarceration of Household Member*	21.1% (4)
9. *Caregiver Separation/Divorce*	31.6% (6)
Total Number of ACEs	
0	31.6% (6)
1	10.5% (2)
2	21.1% (4)
3	10.5% (2)
4+	26.4% (5)
Mean Number of ACEs (Range)	2.37 (0-7)

The age that youth achieved stable home placement was significantly negatively correlated with caregiver-reported relational and contextual resilience resources, with an earlier age of stability associated with more resilience resources (Table 3.4). Younger age at diagnosis was also significantly associated with higher caregiver-reported relational and contextual resilience resources. Current age, sex, and IQ were not significantly correlated with CYRM composite scores.

Table 3.4

Correlation Matrix of CYRM-28 Scores vs. Childhood Experiences and Individual Characteristics

	CYRM-28					
	Individual		**Relational**		**Contextual**	
Childhood Experiences	**YSR**	**CR**	**YSR**	**CR**	**YSR**	**CR**
Total ACE Score	-.45	-.01	-.06	-.18	-.07	-.09
Age of Stable Placement	-.30	-.37	-.17	**-.67****	-.08	**-.48***
Age at FASD Diagnosis	-.03	-.36	-.20	**-.50***	-.01	**-.50***
Individual Characteristics						
Current Age (years)	-.13	-.06	-.29	-.40	-.16	-.14
Full-Scale IQ	-.35	.15	-.05	-.31	-.40	-.06
Sex	-.02	-.05	-.06	.09	.02	-.20

Note. YSR = Youth Self-Report; CR = Caregiver Report

*$p < .05$; **$p < .01$

Resilience Resources and Emotional and Behavioural Functioning

Over 40% of youth reported BASC-2 *t*-scores in the at-risk range or above for internalizing problems (i.e., depression, anxiety). Nearly half of youth rated themselves in the at-risk range for inattention and hyperactivity (Table 3.5). However, overall mean scores for all youth-reported BASC-2 composites fell within the normative average range. In contrast, the mean *t*-scores reported by caregivers fell in the at-risk range for externalizing and internalizing problems, and the clinically significant range for the Behavioural Symptoms Index. Caregivers

also noted youth difficulties with adaptive functioning, with nearly two-thirds of caregivers reporting scores for youth in the at-risk range.

Table 3.5

Youth and Caregiver BASC-2 Composite Scores

	Youth Self-Report (n = 19)		**Caregiver Report (n=16)**	
BASC-2 Clinical Composites	***t*-score *M (SD)***	**At-Risk Range (%)**	***t*-score *M (SD)***	**At-Risk Range (%)**
Externalizing Problems	--	--	65.43 (18.12)	43.8
Internalizing Problems	58.52 (15.86)	42.1	65.00 (14.15)	55.8
Behavioural Symptoms Index	--	--	71.50 (16.51)	62.6
Emotional Symptoms Index	56.95 (14.90)	31.6	--	--
Inattention/Hyperactivity	59.32 (14.93)	47.4	--	--
School Problems	52.50 (10.84)	18.8	--	--
BASC-2 Adaptive Functioning Composites	***t*-score *M (SD)***	**At-Risk Range (%)**	***t*-score *M* (SD)**	**At-Risk Range (%)**
Adaptive Skills	--	--	35.38 (12.33)	62.5
Personal Adjustment	45.42 (13.86)	26.4	--	--

Note. For *t*-scores, $M = 50$; $SD = 10$. Higher Clinical scale *t*-scores and lower Adaptive scale *t*-scores reflect greater impairment. $t \geq 60$ on Clinical scales or ≤ 40 on Adaptive scales are considered *at-risk*.

There was a significant inverse association between youth-reported emotional symptoms and individual resilience, as well as caregiver-reported behavioural symptoms and individual resilience, indicating that poorer mental health functioning (higher *t*-score) was associated with less individual resilience resources (Table 3.6). However, when early childhood adversity was controlled, the relationship between these variables was no longer significant.

There was also a significant positive association between youth- and caregiver-reported adaptive functioning and individual resilience (Table 3.6). That is, more individual resilience resources were associated with better adaptive functioning (higher *t*-score). When exposure to

early childhood adversity was controlled, this association remained significant. Higher youth-reported contextual resilience resources was also significantly related to better adaptive functioning, including when controlling for ACE score.

Table 3.6

Association Between CYRM-28 Scores and BASC-2 Scores Controlling for ACE Score

	CYRM-28: Youth Self-Report					
	Individual		**Relational**		**Contextual**	
BASC-2: Youth Self-Report	***r***	$r_{partial}$	***r***	$r_{partial}$	***r***	$r_{partial}$
School Problems	-.33	-.24	-.11	-.09	-.26	-.22
Inattention/Hyperactivity	-.06	-.01	-.19	.31	.07	.23
Internalizing	-.32	-.14	-.10	.03	-.15	-.12
Emotional Symptoms Index	**-.48***	-.33	-.17	-.09	-.33	-.27
Personal Adjustment	**.63****	**.52***	.38	.37	**.54***	.51
	CYRM-28: Caregiver Report					
	Individual		**Relational**		**Contextual**	
BASC-2: Caregiver Report	***r***	$r_{partial}$	***r***	$r_{partial}$	***r***	$r_{partial}$
Externalizing	-.38	-.39	-.32	-.33	-.05	-.05
Internalizing	-.47	-.40	-.22	-.06	-.32	-.31
Behavioural Symptoms Index	**-.56***	-.52	.07	.25	-.27	-.24
Adaptive Skills	**.64****	**.62***	.12	.06	**.49***	.48

Note. r = Pearson correlation co-efficient for association between CYRM-28 and BASC-2 scores; $r_{partial}$ = partial correlation co-efficient for association between CYRM-28 and BASC-2 scores controlling for ACE score

*p < .05; **p < .01

Discussion

In this study, I described a profile of individual, relational, and contextual resilience resources reported by a sample of youth with FASD and their caregivers. I then investigated how these resilience resources related to early childhood adversity and potential protective factors, as well as concurrently reported emotional and behavioural functioning.

Profile of Resilience Resources

In this study, individual resilience included resources such as (self)-perception of prosocial personal qualities (e.g., cooperation, follow-through, awareness of strengths), feelings

of peer connectedness, and social skills (including the perception of the opportunity to develop basic adaptive skills). Consistent with predictions, caregivers and youth reported significantly different levels of individual resources. Caregivers reported that youth with FASD had a generally low level of individual resources – significantly fewer than both low-risk youth and complex-needs youth from the normative sample. Given that participants with FASD shared the experience of early environmental adversity with complex-needs youth, but also experienced additional cognitive and adaptive challenges that would impact individual resources, it is not surprising that caregivers would consider youth with FASD to have lower individual resources. As predicted, and consistent with previous research (e.g., Rogers et al., 2013), youth with FASD reported that they had fairly high personal and peer strengths, with levels of individual resilience commensurate with low-risk youth from the normative sample. These findings align with previous FASD research: youth often rate themselves as having better individual qualities or capacities than do their caregivers (e.g., Mariasine et al., 2014). This may reflect differing levels of insight – for example, due to adolescent egocentrism (Elkind, 1967) or FASD-related brain-based difficulties that affect self-perception (e.g., challenges with self-reflection, abstract thinking, judgment). Youth and caregivers may also report different perceptions based on experience (e.g., reference points they compare themselves/youth to), different expectations, or in response to the effectiveness of supports. Regardless, youth may view their own capacities differently than others around them, and gaining multiple insights into youth functioning can provide a richer understanding of their functioning and needs. It was anticipated that youth with FASD would report significantly more individual resources than other domains, but this hypothesis was not supported.

Both youth with FASD and caregivers reported high relational resources, comparable to low-risk youth in the normative sample. This suggests that both youth with FASD and caregivers

perceived youth with FASD to feel safe, physically nurtured, well understood, and emotionally supported. This result was higher than hypothesized, and may reflect sampling: participants reported relatively high stability for a clinical FASD sample, and all participant dyads had an ongoing relationship. However, the relational resources assessed include youth *perception* of being supported and cared for – feelings that do not automatically exist in youth-caregiver relationships. The concordance in reporting between caregivers and youth in this domain was also unexpected, given previous questionnaire-based research (e.g., Mariasine et al., 2014). However, qualitative studies have noted that youth with FASD consistently credit supportive relationships as being instrumental in navigating toward resilient trajectories (Broderson, 2013), including supporting school persistence (Duquette et al., 2006) and transition from the child welfare system to autonomous adulthood (Burnside & Fuchs, 2013). Relational support as a key promoter of resilience across the lifespan is a robust finding in the broader resilience literature (Masten & Cicchetti, 2016) and may exert the strongest influence on youth who are most marginalized (Afifi & MacMillan, 2011; Bellis et al., 2017; Masten, 2014). It may be critical among children with FASD whose relational systems and attachments may be dually impacted by cognitive differences that can affect attachment (Ungar, 2013b; Werner, 2013) as well as environmental factors like Children's Services apprehension, multiple home placements, and retention in the foster care system (O'Connor et al., 2002). These results suggest a capacity for strong attachments in youth-caregiver relationships in this population, which further underscores the importance of prioritizing stability and conditions that provide an opportunity for the development of strong relational bonds.

The contextual resilience resources measured in this study included spirituality (e.g., spiritual beliefs, participation in religious activities), education (e.g., personal importance of education, sense of belonging at school), and cultural connection (e.g., pride and enjoyment in

one's culture; positive community). Consistent with predictions, both youth and caregivers reported the lowest amount of contextual resources. Notably, at a subscale level, spiritual resources were reported to be particularly low. Previous research, including studies with primarily Indigenous young offenders with and without FASD (Rogers et al., 2013), also found the CYRM spiritual subscale to be least endorsed. It is difficult to ignore these results in the context of two-thirds of this sample identifying as First Nations and Métis being raised in non-biological homes, a factor that may contribute to disconnection from cultural and spiritual practices. It was beyond the scope or ability of this project to address this issue: caregivers did not report their cultural background, and the sample size was insufficient to examine differences in spiritual resources between Indigenous and Caucasian children with FASD residing in non-biological homes. Having a greater sense of cultural connection, spirituality, community belonging, and overall ethnic identity has been associated with resilience among Indigenous youth with and without FASD (Rogers et al., 2013; Toombs et al., 2016), as well as positive outcomes among Indigenous youth in care (Pelech et al., 2013). Ensuring that Indigenous children with and without FASD raised in government care grow up with connection to their people, culture, and spirituality may help foster healthy development, as well as help promote and protect Indigenous communities and cultures (e.g., Carriere, 2007).

Association Between Resilience Resources and Other Factors

More than two-thirds of youth had been exposed to at least one ACE, most commonly neglect and household substance use. Previous research in developmental populations has found that exposure to multiple types of adversity additively increases the risk of negative outcomes (Filbert & Flynn, 2010). Few have examined how ACEs relate to the availability of resilience resources, although a recent retrospective population-based study reported that individuals with higher ACE scores report fewer resilience resources on the CYRM (Bellis et al., 2018). I was

curious if exposure to risk would be associated with resilience resources. Despite significant exposure to risk, ACE score was not related to caregiver- or youth-reported resilience resources. However, similar to the findings of Streissguth and colleagues (2004), earlier age of stability was significantly associated with greater relational and contextual resilience resources. Lack of caregiving stability is a common and critical concern among individuals with FASD (Pelech et al., 2013; Streissguth et al., 2004), and instability has been related to a host of problematic outcomes. Based on interpretations made in the broader resilience literature, I speculate that achievement of early stability facilitates the development of better caregiving bonds. This in turn could help foster the development of relational resources, which many have argued is a lynch-pin for the development of resilience resources in other areas (Collin-Vézina et al., 2011; Masten, 2018; Masten & Cicchetti, 2016). For example, individual resources like social competence and contextual resources such as school connectedness can be developed through stable, supportive, and nurturing relationships with caregivers, teachers, or peers. Again, this sample was characterized by fairly long-term, stable relationships between youth and caregivers, which is somewhat atypical within clinical FASD samples. This long-term relational stability may contribute to tempering the potential negative impact of adversity on the development of resilience resources, underscoring its importance as a clinical priority.

Earlier age of FASD diagnosis was associated with enhanced caregiver-reported relational and contextual resilience resources. Timely diagnosis may support the acquisition of resilience resources through helping families and schools address challenges directly and obtain relational and community supports. This in turn can have a cascading effect of ultimately easing caregiving burden (improving relational resources), allowing access to more supportive educational placements (promoting connection to school and school persistence), and permitting access to supports to ease transitions from youth care systems to adult care systems (thus allowing

individuals with disabilities to become supported and valued members of communities and able to find a sense of belonging and purpose).

Finally, I investigated whether specific individual factors would also be associated with resilience resources. Age, sex, and IQ were not associated with youth or caregiver-reported resilience resources.

Resilience Resources and Emotional and Behavioural Functioning

Consistent with high rates of mental health symptomology reported in the broader FASD literature (e.g., Kambeitz et al., 2019; Pei et al., 2011; Popova et al., 2016), nearly half of youth with FASD reported at-risk levels of internalizing problems and symptoms of inattention and hyperactivity. In addition, roughly half of caregivers reported that youth had challenges with externalizing and internalizing problems. It has been proposed that FASD is a risk factor for the development of mental health disorders (Pei et al., 2011), particularly because FASD frequently occurs alongside other factors related to poorer mental health, including ACEs. Although the relationship between the presence of resilience resources and mental health symptomology hasn't been studied in FASD, based on research in other populations, I expected greater individual, relational, and contextual resilience resources to be associated with better emotional and behavioural functioning. Consistent with predictions, youth whose caregivers reported them to have more individual resources had fewer caregiver-reported symptoms of behavioural psychopathology, and youth who reported more individual resilience resources reported fewer emotional symptoms. Interestingly, individual resources was the only resilience domain in which caregivers and youth diverged significantly in reporting, yet similar associations with mental health functioning were observed. Individual resources include qualities that are perhaps most likely to be compromised as a direct result of neurodevelopmental impairments. For example, using social skills, behaving flexibly and appropriately in different contexts, demonstrating

independence, problem-solving, and having impulse control all require well-developed executive functioning and learning ability. Nurturing the development of these individual resources, either directly or indirectly (i.e., combining relational and contextual supports), may support mental health. Notably, when exposure to early childhood adversity was statistically controlled, the strength of these associations weakened somewhat. Thus, prioritizing healthy and stable childhood environments may help ensure that individual resources can be leveraged for better emotional and behavioural functioning.

Contrary to expectations, relational and contextual resilience resources were not significantly associated with emotional or behavioural symptomology. It was particularly surprising that relational resources were not related to better youth- or caregiver-reported emotional or behavioural functioning, considering the relatively high amount of relational support reported and the fact that relationships are considered to be an especially potent source of resilience in the broader literature. Because resilience is an interactive and ongoing process, it is possible that an association between relational resources and mental health will be borne out later, or relational resources may interact with other resilience resources to support adaptation.

The most consistent finding related to adaptive functioning. Higher youth- and caregiver-reported individual and contextual resilience resources were significantly related to better adaptive functioning. These associations remained strong even when early adversity was considered. This aligns with findings in the broader FASD literature. For example, among individuals with FASD, having individual resources such as better executive functioning skills (e.g., planning, self-regulation, metacognition) appears to support adaptive functioning (Coles et al., 2018; Schonfeld et al., 2006). Further, FASD intervention research has suggested that enhancing contextual resources – such as offering individualized educational and community-based support – helps improve goal attainment in independent living skills (Denys et al., 2011).

The finding that increased resilience resources in multiple domains was related to concrete behaviours that reflect the ability to adapt and live competently in the world reflects the core of the definition of resilience: adaptation. Importantly, even in areas where resilience resources were lower (i.e., contextual resources and caregiver-reported individual resources), having some level of resources was related to better adaptive skills, suggesting avenues for support and intervention.

Limitations

These findings are limited by several considerations. The first limitation relates to sampling. This study used a relatively small clinically-recruited convenience sample. This may limit the generalizability of the results, especially to youth with FASD who are not connected to clinical services. Furthermore, the presence and severity of emotional and behavioural comorbidity is much more likely in a clinical sample compared to a population-based sample. Thus, the association between resilience resources and emotional and behavioural functioning may differ in broader samples of youth with FASD. Another potential issue with this sample is that all participants were recruited as dyads. The ongoing relationship between youth and caregivers may have helped improve the accuracy of caregiver reporting, particularly in relation to observable behaviour. However, close youth-caregiver relationships could also naturally lead to increased relational resilience scores. Relational resilience resources reported on the CYRM may look very different in a sample that included perspectives of youth and young adults with FASD who do not have an ongoing relationship with a caregiving figure.

Second, relatedly, the sample size limited the choice of statistical design and power. Although small sample size is common in FASD research, increased sample size would permit the use of more powerful statistical analyses (e.g., regression) to better understand the relationships between risk and individual factors, resilience resources, and mental health, as well

as enhance the power to detect significant differences and relationships. Despite this, I found many statistically significant results that are even more noteworthy because of reduced power.

Third, this cross-sectional study only captured resilience resources and emotional and behavioural functioning at one point in time. Resilience is a process rather than an outcome or end-point. Longitudinal research would help examine how resilience resources shift over time, as well as facilitate better understanding of the relationship between resilience resources and emotional and behavioural health. This design also did not allow the direction of the relationship between resilience resources and emotional and behavioural functioning to be determined. For example, did youth with FASD have better adaptive functioning because they had more resilience resources, or did they have more resources because they had better adaptive functioning?

Fourth, the profile of resilience resources in this sample was contextualized by comparing scores to the normative sample. Inclusion of a geographically and demographically similar control group (e.g., youth raised in non-biological homes) may have helped provide a deeper understanding of how having FASD may uniquely impact the availability of resilience resources.

Finally, this study relied on self-report data, which reflects the subjective views of participants. The quantification of resilience resources, for instance, is based on the perception of the availability of these resources, not on the objective presence of them. The presence of cognitive differences among youth with FASD may introduce "error." Although care was taken to ensure that participants understood what they were being asked (i.e., provided assistance with reading and comprehension), it is possible that the responses of youth with FASD were affected by variability in insight, receptive language, and comprehension of abstract ideas. However, patterns of youth responses, particularly in relation to caregiver responses, were similar to studies eliciting the perspectives of typically developing youth. Additionally, regardless whether youth

perceptions match what others perceive, it is still important to understand how youth view their own strengths and the supports around them in order to best support their development.

Conclusions and Future Directions

Youth with FASD face numerous challenges. Yet, they also possess resources within themselves, their relationships, and communities which may be related to better emotional and behavioural health. The findings of this study suggest that although youth with FASD may report themselves to have abundant individual resources, caregivers who know them well may perceive them differently. Differences in reporting may reflect many factors. Eliciting the perspectives of youth and trusted others in their networks and assessing the individual reasons for differences in reporting provides helpful insight into the individual needs and functioning of those with FASD. Clinically, we must work to understand the individual sources of these differences to enrich our understanding of individuals, to appreciate the implications of these differences, and to bridge these gaps as necessary. Supporting the development of individual strengths such as social competence may be connected to better emotional and behavioural wellness as well as adaptive functioning. Although relational supports did not appear to be directly associated with emotional or behavioural functioning, participants reported a very promising level of relational connection between youth and caregivers. It is thought that relationships form a powerful basis for other resources to be developed. I would continue to advocate for an emphasis on stability and consistency in caregiving relationships and working to ensure youth with FASD have positive connections to adults at school and in their community. In future, it will be important examine the association between relationship type, quality, and character and the effect on resilience trajectories among youth with FASD, especially as they transition to adulthood. Another promising avenue for further study is the concept of family resilience, which more deeply considers the interactive and nested nature of relational resilience (Walsh, 2016). Particularly

when individual resources are challenged due to disability, ensuring environmental resources may be critical. These findings also suggest that work could be done to determine how contextual resources can be strengthened, or at least better understood. Future investigations may wish to examine the broader variety of community-based resources that youth may draw upon in their daily lives; if there are community resources more relevant to youth with FASD that are not sampled by the CYRM; or how contextual resources like spirituality are accessed over time. It is also possible that individual and relational resources may hold potential for intervention when youth or their trusted others believe contextual supports are lacking. Greater priority could then be given to identifying and targeting alternative supports and relational networks that youth can draw from to support their ability to confront challenges.

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Chapter 4: Thriving With Fetal Alcohol Spectrum Disorder

Since Fetal Alcohol Spectrum Disorder (FASD) was first identified nearly five decades ago (Jones & Smith, 1973), significant effort has been devoted to understanding the symptoms and challenges associated with this condition. FASD is now recognized as one of the most common neurodevelopmental disabilities, affecting an estimated 2 to 5% of North Americans (May et al., 2018; Popova et al., 2019; Roozen et al., 2016). Although individuals with FASD experience a range of difficulties, most struggle to some extent with intellectual functioning, academic achievement, learning, memory, attention, executive function, emotional regulation, and adaptive functioning (Cook et al., 2016). These difficulties are frequently coupled with a higher incidence of adverse childhood experiences, such as being raised in a non-biological home and being exposed to abuse and neglect (e.g., Kambeitz et al., 2019; McLachlan et al., 2015). Together, these challenges are thought to contribute to the development of secondary disabilities including difficulties with education, employment, independent living, substance abuse, and justice involvement (Kambeitz et al., 2019; Streissguth et al., 2004).

Mirroring developments in the field of developmental psychopathology, more recent research has focused on examining resilience trajectories among youth with FASD. Most research has focused on factors that enhance or attenuate the risk of developing poorer outcomes among individuals with FASD (e.g., Streissguth et al., 2004), and assets associated with achievement of typical milestones such as school persistence (e.g., Duquette et al., 2006; Knorr & McIntyre, 2016). Individual qualities, such as understanding one's own strengths and challenges (Brenna et al., 2017), supportive relationships with caregivers, teachers, and community members (Burnside & Fuchs, 2013; Duquette et al., 2006; Knorr & McIntyre, 2016), and contextual supports like individualized educational supports (Duquette et al., 2006; Job et al., 2013; Millar et al., 2017) have been described as supportive of resilient trajectories among youth with FASD.

Although there is increasing understanding of factors that support youth with FASD to be resilient – that is, to avoid negative outcomes and develop competently – no one has investigated what it would mean for youth with FASD to go beyond resilience to *thrive.*

Thriving

Understanding what it means to develop *exceptionally* – that is, *thrive* – as an adolescent is a key focus of positive youth development (PYD) research (Benson & Scales, 2009; Benson et al., 2006; Sesma et al., 2013). Thriving research has centered on understanding how typically developing youth are able to transcend merely competent developmental trajectories (i.e., moving beyond avoidance of problems and pathology) to a state where they "embrace life and make full use of their special gifts in ways that benefit themselves and others" (Benson & Scales, 2009, p. 90) as they transition to adulthood. Informed by PYD and relational-developmental systems theory, thriving is conceptualized as an upward trajectory that unfolds over time through an interaction between individual capacities and a supportive environment (Benson & Scales, 2009). Thriving describes the process of an individual pursuing a path of growth in individual qualities (e.g., caring, character, competence) that support achieving an idealized, self-actualized personhood, reflected by engagement in socially valued behaviours (Benson & Scales, 2009).

Different researchers have worked to identify youth qualities associated with thriving, including: social, behavioural, and academic competence; relational and community connection; growth and fulfilment of potential; sense of purpose; confidence; positive identity; positive emotionality; prosociality; and spiritual development (e.g., Benson & Scales, 2009; Dowling et al., 2003; King et al., 2005; Lerner et al., 2005; Theokas et al., 2005). The identification and pursuit of *sparks* – talents and interests that give youth energy and purpose – is also a core element of thriving (Benson & Scales, 2009; Scales et al., 2011). There is an underlying assumption that a thriving youth is one whose sense of purpose, goals, actions, and sparks are

pursued in service of making "valuable" contributions to broader society (Arnold, 2018; Benson & Scales, 2009; Scales et al., 2011). Although there is some emphasis on achievement of specific outcomes (e.g., school success), the predominant focus is on the process of growth. Key qualities of youth environments that support the development of thriving include *relationships, opportunities*, *support, encouragement,* and *positive pressure* for youth to grow and develop their talents and skills, provided by people in multiple developmental contexts (e.g., family, friends, teachers; Arnold, 2018; Benson & Scales, 2009; Roehlkepartain et al., 2017).

Thriving is a generous construct – "anyone" can thrive (King et al., 2005). Young people are seen as "resources to be nurtured" instead of "problems to be managed" (Benson & Scales, 2009, p. 90) regardless of their challenges. Yet, little research has examined what it means to thrive as an individual born with more than the typical range of challenges, such as those with complex developmental disabilities like FASD.

Thriving With FASD

Developmental disabilities like FASD are defined by functional limitations, meaning that youth tend to struggle to develop "competently" let alone thrive by normative standards. Yet, substantial heterogeneity in symptom profiles (e.g., Mattson et al., 2019) and outcome trajectories (Lynch et al., 2015; Rangmar et al., 2015) indicates that it is possible for individuals with FASD to do well. Having FASD affects how an individual learns, develops relationships, interacts with the world, and experiences life from birth. Thus, there is reason to believe that thriving may look different for individuals with FASD. For example, self-regulation has been described as a marker of thriving among typically-developing adolescents because it reflects that youth are able to effectively respond to their environments and direct their behaviour toward an optimal trajectory (Bowers et al., 2010; Lerner, Lerner, Bowers, et al., 2011). Self-regulation may foster the development of other aspects of thriving, like goal-setting (particularly goals that

reflect a life purpose; e.g., Gestsdóttir & Lerner, 2007; Lerner, Lerner, Bowers, et al., 2011). It may also help youth leverage growing cognitive and behavioural skills (such as executive functions) to optimize pathways to achieving goals, recruiting resources, and compensating effectively. Individuals with FASD typically demonstrate relative weakness in their ability to self-regulate and successfully deploy executive functions (for reviews, see Mattson et al., 2019; Rasmussen, 2005).

If the qualities that mark thriving in typical development are impaired, is it possible for youth with FASD to thrive identically to a typically developing adolescent? Given challenges in some domains that mark a thriving trajectory, do certain indicators of thriving (e.g., life purpose; leadership; pursuit of social justice) become more or less important? Or do they manifest differently? Some have argued that *all* youth have individual and contextual strengths that may be capitalized upon to promote thriving in their development (e.g., Lerner, Lerner, Lewin-Bizan, et al., 2011). Are those strengths different among individuals with FASD? In addition, thriving is conceptualized as occurring when an individual's personal qualities are supported by "supportive and nurturing ecologies" (Benson & Scales, 2009, p. 90) through a dynamic and transactional process. Developmental disability may affect the relationship between an individual and their environment, including by affecting access to opportunities and creating different expectations compared to typically developing peers. In addition, given the common contextual experiences of many individuals with FASD (e.g., disrupted caregiving relationships), the qualities and relative importance of relational and environmental support to a thriving trajectory may differ as well.

There is no research regarding what it means to thrive as an individual with FASD, and little in the developmental disabilities literature to draw upon. According to PYD and relational-developmental systems theory, understanding what it means to thrive with FASD requires

understanding the unique individual qualities that mark a thriving person with FASD as well as the factors in their lives that support the expression of these qualities.

Purpose and Research Questions

Beginning to understand thriving with FASD requires a qualitative approach. Qualitative research explores issues and perspectives that are open, unclear, or have been untouched by the current literature (Creswell & Poth, 2018; Merriam & Tisdell, 2016). There is an emphasis on process, meaning, and understanding. Qualitative research asks participants who are most intimately familiar with a phenomenon to share their lived experience and perspectives. Eliciting the perspectives of youth with FASD and their caregivers – in this case, through interviews – is critical to gaining an early understanding of what it means to thrive as an individual with FASD and the factors that support thriving.

The purpose of this study was to understand what it means to thrive with FASD from the perspectives of young people with FASD and their caregivers. Gaining these insights will broaden our overall understanding of FASD and ultimately help inform how to support trajectories characterized by successes that are valuable and meaningful to individuals with FASD and their families. Three main research questions guided this qualitative inquiry:

1. What are the qualities associated with thriving for a young person with FASD?
2. What factors support thriving among young people with FASD?
3. What does it mean to thrive with FASD?

Methods

I used a basic qualitative approach (Merriam & Tisdell, 2016) to understand how individuals with FASD and their caregivers view thriving with FASD. I was guided by the epistemological philosophies of social constructivism, where reality is viewed as a social construction of multiple interpretations of events, and phenomenology, which asserts that people

make individual interpretations and meaning based on their experience with a phenomenon (Creswell & Poth, 2018; Merriam & Tisdell, 2016). PYD and relational-developmental systems theory provided the theoretical underpinning for this study, influencing the development of interview questions, theme development in late-stage data analysis, and interpretation.

Participants

Five participant dyads participated: five youth and young adults with FASD aged 16 to 24 years (hereafter referred to as "youth with FASD") who had been previously diagnosed by a multidisciplinary FASD diagnostic team; and four caregivers (two youth shared a caregiver). Three additional caregivers of youth with FASD participated independently, for a total of five youth and seven caregivers. Most caregivers had parented more than one child with FASD. They were invited to speak about their perspectives on thriving based on their experiences of raising multiple children with FASD. All youth participants described themselves as doing well currently, and their caregivers agreed. Caregivers who spoke about their non-participating children with FASD reported that the majority of their children were doing well; however some youth (by caregiver's definition) were not. Therefore, thriving was discussed in relation to the qualities of youth currently thriving, qualities that would be supportive/indicative of future thriving, and qualities youth demonstrated in past instances of thriving. See Tables 4.1 and 4.2 for participant descriptions.

Table 4.1

Description of Youth Participants with FASD

Youth (age, sex)	Other Diagnoses	Ethnicity	Background	Education	Occupation	Relationship Status	Living Status	Key Supports
Alanis (23, F)	• Anxiety	First Nations	Stable foster care (age 11)	High school certificate	Student; accepted into college	Long-term partner	Semi-independent suite with foster family	• Financial: AISH • Relational: Foster family, partner, sisters
Alicia (24, F)	• Depression	First Nations	Stable foster care (age 12)	High school certificate	Paid work, volunteer at local school	Long-term partner	With foster parents (pays rent)	• Financial: AISH • Relational: Foster parents, partner, sisters
Ethan (24, M)	• Mild ID • ADHD • Physical disability	Caucasian	Adopted (age 7)	High school graduate	College student	Long-term partner	Independent (with partner)	• Financial: AISH • Relational: Mom, partner
Jade (24, F)	• Anxiety • Depression	First Nations	Stable foster care (age 1)	Working on GED	Volunteer: community organization	Long-term partner	Semi-independent suite with foster mother	• Financial: AISH • Relational: Mom, partner
Victoria (16, F)	• Moderate ID • Multiple physical health challenges	First Nations	Adopted (age 1)	High school student	Student	Single	With parents	• Financial: N/A • Relational: Parents, extended family

Note. Names are pseudonyms. Specific physical disabilities not specified to protect confidentiality. AISH = Assured Income for the Severely Handicapped (government financial assistance); GED = General Education Diploma (High School Equivalency Certificate); ID = Intellectual Disability

Table 4.2

Caregivers of Youth with FASD

Caregiver (Youth)	Other Children with FASD	Occupation
Angie (Alicia, Alanis)	20+ foster children over two decades	Small business owner
Elaine (Ethan)	-	Healthcare professional
Jeannette (Jade)	-	Retired
Violet (Victoria)	Adopted son (age 18)	Graduate student
Beverley	Two adopted sons and two adopted daughters (ages 19-26)	Educator
Mary	Adopted daughter (age 12) and adopted son (age 18)	Retired
Carla	Two adopted sons with FASD (ages 18 and 20)	Small business owner

Note. Names are pseudonyms.

After obtaining institutional ethical approval, I recruited participants via purposeful sampling by two approaches. First, I invited youth-caregiver dyads who had previously participated in a study with a large urban FASD diagnostic clinic (and who had agreed to be contacted for future participation in research) to participate. Second, I recruited participants from two rural community mental health organizations via distribution of recruitment materials and direct communication with service providers. Interested participants consented to be contacted after agreeing to organization-specific consent and confidentiality policies. I chose not to use inclusion/exclusion criteria based on current thriving status or outcomes for two reasons. First, I felt it was important to include diverse voices to reflect thriving across the FASD spectrum. Second, I wanted participants to be able to speak about what thriving would look like – currently, prospectively, or retrospectively – for themselves or their children without imposing my own criteria of thriving/not thriving. Regardless of recruitment approach, I contacted participants directly to set up an interview at a time and place that was mutually convenient. All participants

older than 18 years provided informed consent. The youth participant under age 18 provided assent, while their caregiver gave informed consent.

Procedure

I conducted one semi-structured, digitally audio-recorded interview with each participant. I interviewed four youth and five caregivers in person, and one youth and two caregivers by telephone. Youth interviews ranged from 20 minutes to 55 minutes, and caregiver interviews ranged from 45 minutes to 2 hours. I developed the interview protocol of eight open-ended questions with optional follow-up questions and prompts (see Appendix A). Questions were designed to elicit views related to the research questions. Given the preliminary nature of this research, I asked multiple questions to provide several opportunities for participants to express their ideas about thriving. Most optional prompts were based on previous PYD thriving research (e.g., King et al., 2005). For example, academic engagement is an indicator of thriving in the PYD literature, so an optional follow-up prompt to a question about thriving included a query about education. During the course of each interview, I followed up participant responses to open-ended questions with supplementary questions as necessary (Merriam & Tisdell, 2016).

I transcribed the interviews verbatim using Microsoft Word within one-week post-interview. After transcription, I removed redundancies (e.g., it, it…) and superfluous utterances (e.g., "um"), taking care not to change the meaning of participant responses. I removed potentially identifying information (e.g., names of people, places, services). In some cases, I blurred demographic details (e.g., occupations, comorbidities) to protect identities of participants who are more visible in the local FASD community. I gave all participants pseudonyms; youth-caregiver dyads are linked by the first letter of their pseudonym (e.g., Victoria and Violet). As

recommended by Merriam and Tisdell (2016), I refined the interview (including re-wording, eliminating, or adding questions) as data collection progressed.

Data Analysis

Data analysis followed the basic qualitative approach described by Merriam and Tisdell (2016) who recommend "consolidating, reducing, and interpreting what people have said and what the researcher has seen and read" (p. 176), as well as basic thematic analysis (Braun & Clarke, 2006), which guides researchers to identify patterns and themes that emerge from participant experiences. According to Braun and Clarke (2006), "[a] theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning" (p. 82). Essentially, themes help tell a story about participants' experiences. In qualitative research, the "primary instrument" of data analysis is the principal investigator. Therefore, interview data and resultant themes are a co-construction of knowledge resulting from the interaction between myself and participants.

Data analysis began during data collection (Merriam & Tisdell, 2016; Saldaña, 2016), as collection, transcription, and analysis occurred simultaneously. During transcription, I used memos to note initial ideas about patterns in the data. Once data collection and transcription were complete, I immersed myself in the data by reading through each transcript, again keeping record of my thoughts in memos. I then imported the data into the qualitative software program NVivo12 and began an inductive coding process. I coded the five youth interviews first, followed by the seven caregiver interviews. This initial phase of coding included a broad review of data in line-by-line coding, with a focus on identifying data that were responsive to the research questions. Initial coding was detailed, concrete, and "close" to the data; I often used the words of participants to reflect this (e.g., "Staying on the Right Path"). A total of 579 codes

emerged from this process. I then reviewed the codes, moving through a process of re-thinking, re-coding, and merging codes that were semantically similar or conceptually identical (e.g., "Make Positive Choices" and "Good Choices"). I then sorted codes into subthemes by again reviewing the list of codes and considering how code labels and the data subsumed by them were similar and different. Through a process of exploring the relationships between different codes and data, similar codes were grouped together or merged into subthemes. I then shifted from an inductive analysis to a deductive (theory-guided) process (Braun & Clarke, 2006; Merriam & Tisdell, 2016). I examined how inductively-generated subthemes fit within the theoretical frameworks of PYD and relational-developmental systems theory. This guided me in grouping many subthemes into more abstract themes, and allowed me to notice how findings aligned with theory. Subthemes and themes were determined primarily based on how well they captured something important in response to the research questions, rather than prioritizing how prevalent they were among participants (Braun & Clarke, 2006). That said, each resultant theme was supported by the majority of youth and caregiver participants unless otherwise noted.

Methodological Rigor

Credibility was enhanced through triangulating findings via member-checking. I distributed copies of the initial findings to participants who had consented to follow-up and asked if the resultant themes "rang true" for them (Merriam & Tisdell, 2016). Four participants responded; all provided support for the findings and did not request changes. Credibility was also supported by being transparent in how my own values and expectations influenced the conduct and interpretation of the study (see Chapter 1 of this dissertation; Creswell & Poth, 2016; Merriam & Tisdell, 2016). Reliability or consistency of findings was supported by the above-noted strategies, as well as use of an audit trail (Merriam & Tisdell, 2016). Throughout the study,

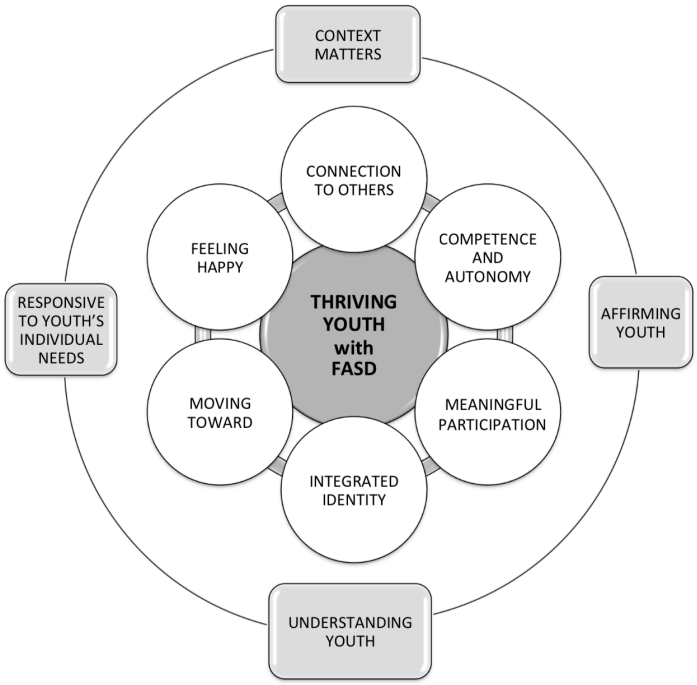
I recorded my thoughts, comments, and observations about interviews; reflections and questions; methods used for coding; criteria for themes; and decisions made regarding issues that arose during data collection and analysis. Transferability was pursued by providing thick, rich descriptions of participants and findings (Ponterotto, 2006) and including participant quotes. I also included participants with a range of diagnostic severity and current functioning to allow for a broader range of application (Merriam & Tisdell, 2016).

Findings

Five youth and seven caregivers shared what it means to thrive with FASD, based on their experience of having, or raising children with, FASD. Participants used various terms for the construct of thriving, including "thriving," "doing well," and "success," so I also use these interchangeably. Participants discussed two main aspects of thriving, which align with PYD and relational-developmental systems theory. First, participants described individual qualities of youth they believed represented thriving with FASD. I grouped these individual markers of thriving into six themes: *connection to others, competence and autonomy, meaningful participation, integrated identity, moving toward,* and *feeling happy*. Second, participants discussed qualities of youth environments that supported the development of thriving. I clustered these into four themes: *context matters, affirming youth, understanding youth,* and *responsive to youth's individual needs*. Although discussed separately, the individual qualities that mark a youth with FASD as thriving and the contextual factors that support thriving are interconnected; each potentially bi-directionally influencing the development of others (Figure 4.1).

Figure 4.1

Individual Markers of Thriving and Contextual Qualities that Support Thriving



Individual Markers of Thriving

Connection to Others

To thrive with FASD means that a youth feels connected to others in meaningful ways. According to participants, meaningful *connection to others* is described by two subthemes: *experiencing love and stability* and *contributing to relationships*.

Experiencing Love and Stability. Participants felt that an important element of thriving is for youth to experience a sense of love and stability in close relationships. As Mary said, for youth to "have a loving life… to feel loved and to love others" is a key indication of thriving.

One common element that participants spoke about was connection to family. All youth had been raised in non-biological homes. Some were adopted at birth; others entered foster care later in childhood after periods of disrupted attachment. Regardless, feeling connected to family – whether foster, adoptive, or biological – was central to thriving for all youth. "Connectedness

to family is important to me," Alanis said. "I do have two families, my foster family and my blood family… Some people in my blood family are there for me… and my foster family, I dearly love them all." For Victoria, finding love and stability within both her adoptive and biological families was viewed as success. "We really see that for Victoria, a part of success is… feeling good about moving forward with respect to all of those relationships," said her mother Violet. "Victoria will talk with great satisfaction about the fact that she has two families… She likes the networking of relationships… she thinks everyone should have two families!"

Experiencing a strong and secure connection to caregivers and family provides the foundation for the development of other intimate relationships. The majority of youth and caregivers spoke about their hopes for youth to find romantic love in healthy and safe relationships, representing the typical developmental transition of primary attachments with caregivers to romantic relationships. Indeed, several caregivers described thriving community members with FASD as experiencing positive, stable, and loving connections with their families and intimate partners. When describing what a thriving future would look like, nearly all youth expressed the desire for stable and growing connection to others: they hoped to maintain healthy relationships with their current partners, get married, and have a family of their own. Thus, thriving with FASD includes experiencing healthy connection with others in the present, and believing that such connection will persist into the future in developmentally appropriate ways.

Contributing to Relationships. Participants also emphasized the importance of contributing meaningfully to relationships: when youth feel that they can offer something valuable to others, they experience a sense of belonging within relationships.

Many youth said they contribute to relationships by helping others. For example, Jade, whose mother Jeannette described her as a "support counselor" to others, described herself as

contributing to relationships by being "supportive, caring" and "empathic." Jade took pride in supporting her friends through difficult times: "I think having to deal with different challenges, both my mental illness and FASD… has helped me support others who have experienced the same thing. I try to help them understand how to cope with what they're going through." Mary said that someone with FASD is thriving when they are "contributing to people in the community" by "supporting others." Many caregivers cited individuals in the FASD community (e.g., inspirational speakers) as thriving because they are "contributing" by "connecting with others and trying to help" (Elaine). Carla felt this represents "a huge success in itself."

Violet added that thriving goes beyond simply contributing to relationships to include youth's subjective awareness that "what they contribute is valued by others," and feelings of acceptance and belonging. She described her son and daughter as both thriving because they "feel valued" and "feel like they're part of a community," "surrounded by people that enjoy their company and who are really happy to spend time with them." Jade described her success in her volunteer placement: "People at the office… are always happy to see me. They're extremely thankful for what I do. I feel accepted. And appreciated." Mary said that she would define thriving as youth feeling that others "appreciate whatever they can give," and through this, youth "feeling that they're important to society."

Competence and Autonomy

Thriving youth with FASD find a sense of autonomy in their lives through building skills to deal effectively with their environments and themselves. This is described through two interconnected subthemes, *building competence* and *finding autonomy*.

Building Competence. Participants felt that youth with FASD are thriving when youth feel that they are gaining the skills to subjectively experience success in their environment –

whether in education, in living more independently, or managing their emotions. As Violet said, youth with FASD who feel like they can successfully "manage responsibilities" and believe "they've mastered the daily tasks that are in front of them" can "thrive in the opportunity to feel like [they] are functioning in the adult world." Youth participants described gaining competence in two general areas: broad-based environmental tasks of development (i.e., academics and adaptive skills) and self-management (i.e., emotional and behavioural self-regulation).

Youth who were *working toward* individually-meaningful independence and educational goals were described by themselves and their caregivers as thriving, even though they had all *achieved* varying levels of education and independence. In other words, for youth with FASD, thriving in these domains seemed to be less about accomplishing specific outcomes and more about working toward building skills in these areas. This process-focused view of competence suggests that thriving with FASD means that youth have a desire to gain mastery of tasks that are both important to them and commensurate with their individual capabilities. For example, Violet described her son – who is in "a supported employment situation" and "a supported living situation" – as living "the best, best possible outcome" his family "ever could have hoped for." In contrast, Violet said her daughter Victoria's "success as it relates to independence" will "look very different for her," given the nature of her disability, but "it will still be a success" because Victoria will experience mastery of tasks within her capacity.

For youth, finding success in building skills provides access to an adult life that matters to them. Acquiring life skills (e.g., budgeting), working on academics (e.g., taking GED courses or completing college certificates) and meeting milestones (e.g., moving out) were seen as steps toward concrete life goals. For example, nearly all youth spoke about how finishing school,

earning money, and saving money through budgeting and planning would allow them to eventually buy their own homes, get married, and have families.

Youth and caregivers also said that youth with FASD who thrive are building coping skills to help regulate their emotions and guide their behaviour. Youth and caregivers remarked that youth had "grown and gotten stronger" in coping over time, evidenced by "using coping strategies, being able to handle situations, and only crash for so long," as Jeannette said. Several youth said that their vision for ongoing success would include continuing to build and use coping skills. Jade said that success for her would be "to find more ways to cope healthily with my mental illnesses… and cope in healthy ways with my life in general." Alanis hoped that she would be able to learn more skills to be "less anxious and calmer" as she gets older, and proudly described the numerous "strategies" she's already learned to calm herself.

Finding Autonomy. For youth with FASD, thriving also means feeling a sense of autonomy, i.e. perceiving a level of independence and choice in one's life. Building skills as outlined above helps youth feel they have control and self-direction in their lives. For Violet's son to be living a life where he has the sense that "adults get to do the things they want because they have money, and I have money because I have a job, which means I get to make choices," reflects that "autonomy is huge" in thriving. Ethan, Alanis, Alicia and Jade all spoke with pride about feeling that because they had focused on education, learning life skills (e.g., budgeting, driving), and getting jobs, they could do more things on their own and make their own choices. "Through education, achieving work, and working on [her]self," Alanis felt she could continue to grow in her independence and eventually have a family of her own where she could make independent choices about how to successfully provide for them. Jeannette said Jade's growth in being "assertive" and "independent" demonstrated thriving. "She's just grown so much in her

independence. She found that volunteer job all by herself… I didn't even know it was happening, it was all of a sudden, 'I'm going!'" Although Victoria stated that she never wanted to live apart from her parents, she also envisioned an adult life where she would "be free" to do some things on her own and make more choices for herself in how to occupy her time. For youth with FASD, the *experience* of autonomy in one's life is important without an expectation of youth demonstrating full independence. Participants spoke about "interdependence," as Jeanette termed it, or "supported autonomy." As Violet said, "The fact that [my son] is supported doesn't take away for him the feeling of success. 'I live in my own space… I'm earning money that I can put toward things that really matter to me. I can make decisions.' That's huge for him." In other words, requiring some support to act or make decisions does not detract from the fact that youth are ultimately powering and directing their own efforts and choices.

For participants, learning to emotionally and behaviourally self-regulate represented having choice in how they respond in their environments. For example, Violet shared that for Victoria, gaining "some autonomy over her responses" to sensory information is a "tremendous success" because it allows her to "have a measure of management over something that has been beyond her control since she was born." Alanis said that having a repertoire of "lots of things you can do" in terms of coping strategies allows "everyone to make a choice" in how to respond to challenging scenarios.

Meaningful Participation

A key element of thriving with FASD is for youth to feel that they are participating meaningfully in life. To participants, participation is meaningful when youth are *actively engaged in life* and are involved in activities that *capitalize on their strengths and interests.*

Actively Engaged in Life. Youth with FASD who are thriving are perceived by themselves and their caregivers as actively and "fully participating in life" (Carla). Active participation means youth are using their time constructively (e.g., working, volunteering, engaging in hobbies), and are actively engaged with the world rather than being passive and isolated. Elaine emphasized that her son and other thriving individuals with FASD are "doing things, they're getting out there and having a life!" Elaine and other caregivers noted that engagement in activities – "whether it's employment, or recreation, or volunteering… participating in a sport or art or packing groceries" – encourages participants to "experience life." "You're out there, you're doing things… That's success." Participating in an occupation allows youth to be actively included in life instead of "letting their disability or mental illness hold them back," as Carla said. Youth saw success in "getting out of the house" and doing things with their lives; not, as Ethan noted, "sitting around at home doing nothing." Active participation is also meaningful because it is the antithesis of the isolating, non-participatory behaviours of depression and mental health comorbidity that many youth reported. Youth with FASD who struggled with depression, such as Alicia and Jade, said that they knew they were thriving when they were able to get out of the house and engage in work and activities they enjoyed. Carla, whose son has depression, envisioned a thriving future for him where he once again would be "willing to do things" and participate in activities outside of the home.

Capitalizing on Strengths and Interests. A key way youth with FASD can thrive is to discover their strengths and interests and channel these into participation. Participants believed that *anyone* has strengths that can be focused on and used meaningfully. Caregivers agreed that "finding your child's strengths," as Mary said, and "working on that" will "help them to succeed." Youth talked about discovering their strengths and applying them to their lives. For

example, Ethan spoke about channeling his strengths into participating in school, work, and hobbies. “I’ve always been good at hands-on stuff. I love working with my hands. So now whenever I get the chance to build new things… I do it… That’s what I’m going to school for. When I’m done school, I’d love to just have a little workshop where I can build new things.”

Many youth and their caregivers spoke to an interesting phenomenon of youth “channeling” their challenges into strengths. For example, Elaine and Angie both spoke about how their children’s hyperactivity and high need for novelty – while challenging in some situations – also contributed to their children’s desire to be constantly learning new things, participate in many activities, and be active. Ethan agreed: “I like to move around and get new experiences… That’s why my goal for myself is custom work… it will always be new sizes, new shapes, new forms. And that’s good for me. It keeps my mind occupied.” Carla said that her son’s impulsivity, while “bad at times,” could “be positive too.” She noted that it enabled her son to engage in a passion of his, extreme scooter riding. “I mean they don’t stop and think about things before doing them, which can be scary as heck, but it also allowed him to be a huge scooter rider, right? A very talented one. Because he didn’t ever stop and think that doing that triple flip was going to kill him.” Capitalizing on his athletic strength and impulsivity allowed Carla’s son to thrive through participation: once he began to develop his strengths in scootering, he began getting out the house, volunteering, and working.

Integrated Identity

Participants described a thriving youth with FASD as one who is developing a balanced and overall positive identity. To move toward this, youth with FASD described becoming aware of their disability and their unique strengths and challenges, and incorporating this awareness into an integrated understanding of themselves.

Youth and caregivers described youth becoming aware of their unique strengths and challenges over time and through experience. Beverley described her four children as "all doing very well, and not *in spite* of their diagnosis," but rather "because they're coming to a place in their life where they know who they are, and they accept themselves." The "acceptance" of self conveyed by participants appeared to go beyond accepting something "negative" about oneself (i.e., challenges associated with disability), to recognizing one's own strengths and challenges as just something that *is,* representing an integrated and balanced identity. As Beverley said about her four children, "They know they have a disability. They all know what they can't do, and they know where their strengths are. It's been important for them to be able to say: 'This is just who I am.'" Elaine said that when Ethan began technical college "He was confronted, for the first time, with 'I am disabled. I have a lot more struggles than other people do.'" She said that Ethan probably "always knew he had some difficulties here and there," but wasn't aware of "the extent of them and the real functional implications on his life and his potential and how hard he was going to have to work." Elaine said that Ethan becoming aware of these challenges led to him "accepting he has a disability" but "not accepting it will have any impact on the way he lives his life." Ethan said that he's "pretty aware of [his] own struggles" and although he "sometimes wishes he didn't have [a physical disability] and FASD" he "doesn't really look at [having FASD] as good or bad." Ethan saw the challenges associated with his disabilities as just being a normal part of life: "I look at the big picture and I realize, everyone has troubles doing something… there's always going to be challenges, no matter what you look like in life." Similarly, Violet said that Victoria "sees having special needs as a very natural part of who she is, and something to be very comfortable with."

For other youth, coming to terms with having a set of unique challenges involves integrating and recognizing disability as being only one aspect of their identity. In order to thrive, Jade said she had to learn to "not let [herself] be defined" by her disability. She elaborated, "Before… I really focused on the fact that, you know, maybe without FASD I'd be able to graduate, or be more successful, or do better in life. But I am more than my diagnosis." Beverley framed this as youth needing to learn that it's "not so much that you have FASD, but this is just how your brain works;" in other words, thriving youth understand that FASD is part of their experience of life, but it does not wholly define who they are as people.

Moving Toward

To thrive with FASD also means that youth can see a positive future for themselves, and make choices that move them forward along a path toward goals that are meaningful to them. Embedded within this are four interrelated subthemes: *envisioning a future, staying on the right path, persisting through challenges*, and *developing a growth mindset.*

Envisioning a Future. Thriving youth with FASD see a future that matters to them, and have set goals that align with that vision. Sometimes, that future may be on a daily basis. Violet said that "waking up with something to look forward to every day" is an achievable measure of thriving for her son and daughter. Thriving youth may also see a longer-term future for themselves. Violet said thriving is "having a future they look forward to… there are things in the future they are excited about doing." "They see futures for themselves," Beverley said when describing how she knew her four children with FASD were thriving. "They all have their own hopes, their own dreams."

When youth can envision a positive future for themselves, they set goals that will bring them closer to that future. All youth had goals for themselves, ranging from developing interests

and hobbies; to traveling; to learning new skills at work; to milestones such as buying a house, having a career, and starting a family. Youth connected these goals to a vision for an ideal, successful life ahead. "I have a goal in life," said Alanis. "I see myself completing my [college] program and finding a job… I see myself saving up money for a house and for my kids. I see myself working hard." Elaine said about her son Ethan, "He has expectations of himself and the life he wants." Speaking about his "goal to become a full journeyman," Ethan said he was "excited and encouraged about the future." "Seriously," he said, "I just can't wait."

Staying on the Right Path. Most participants felt that avoiding "unhealthy choices" such as substance abuse and crime was an important aspect of being a successful person with FASD. However, to be thriving, youth with FASD have to not just merely avoid negative outcomes; they must also move toward "positive" and "healthy choices," as Jade, Alanis, Alicia, and Ethan put it. "Avoidance of negatives creates a baseline," said Violet. "But you need more than just a baseline to thrive. You need to be striving toward positives… something that matters to you… in many ways, that is really the key piece in being successful in your life." With her son, Violet said, "We're focused on what he's moving toward… we want that to be the vacuum that draws him forward rather than staying out of jail to be the vacuum that sucks him backward." In essence, to thrive with FASD means that youth are making choices that move them toward a thriving life and – by extension – away from less desired alternatives. As Alanis said, "Success is kind of just like staying on the right path… [The right path] means staying out of jail and prison. Or when life knocks you down, you don't just go running to substances to make everything better… You make positive choices. You get help. You use your coping skills."

Persisting Through Challenges. Thriving with FASD means to be driven to overcome challenges and be persistent in working toward goals despite challenges. Participants described

thriving youth as having the desire to overcome challenges to work toward goals that mattered to them. Beverley described her four children with FASD as successful because "They have learned to challenge themselves… So they're, 'It's not okay where I am in life, there's something else out there.' They all have that tendency or that view." Some youth described an intrinsic motivation to work on challenges. Victoria said she "loves puzzles" and "taking stuff apart" because "it feels really good" to figure out tough things. Ethan said, "I enjoy challenges very much so." This is what drew him to pursue his trade and challenging hobbies that enrich his life.

Some youth described being motivated by the challenge of feeling as though others doubt that they can work toward their goals. Rachel said that what keeps her persisting, even when she felt others thought she was "dumb," was that she "just really wants to prove [herself]." "I want to show I can do it despite my learning disabilities and physical disabilities." Ethan said, "I almost want people to tell me I can't do things. I look at what I did – and I'm not trying to brag or anything, but I look at my past life and how I was always told, 'You can't, you can't, you can't.' And I'm just like, I'm going to turn this around so it's almost like a slap in the face." Elaine described Ethan's desire to confront challenges to achieve his goals as a "healthy defiance:"

> He said…"I want to have my own place. And I want to drive a car and I want to have a life." And I said, "Well honey, you know, I don't know if you'll ever do those things, but you'll be okay." And he said, "NO! I'm going to do those things!" And it's almost like he has decided you cannot tell him no. He is going to do it. And he does it!

Working through challenges demands persistence. According to participants, to thrive with FASD is to persist through challenges, regardless of whether concrete accomplishments are met. Ethan and Elaine talked about Ethan's experiences in technical college. By one measure,

Ethan's academic path is marked by repeated "failures," but his hard work, dedication, and perseverance through challenges marks him as immensely successful. Elaine said:

> He just keeps going and going. He will not accept defeat… He failed his first year, but he was like, no, I'm going back. I'm going to do it. Now he's going back for a third crack at his second year. He'll probably do it this time. And he says he's going to go right through no matter how many times he has to do each year.

In fact, Jade, Ethan, Alanis, and Alicia have all been engaged in a five to six year process of gradually working their way toward academic targets. Each class taken toward a GED, every course upgraded, and every post-secondary class or year repeated represents thriving because it reflects youth persistence through tasks that are, as Violet put it, "overwhelming and incredibly taxing." In regard to her son's persistence through high school, Violet described her son as having "incredible tenacity, incredible commitment, and incredible willingness to keep trying." She reflected, "If I had some of the experiences in the context of my life that he has had in his… to keep going, to get up again and try another day? Incredible." To participants, showing persistence marks a person as likely to thrive even amidst periods of struggle. Alanis described a friend with FASD who "keeps falling off the wagon." However, she sees this friend as successful because "he keeps trying again, and working on himself and his education and goals." In other words, success is not necessarily defined by managing not to stumble, but by the act of pushing on and trying again in spite of challenges.

Developing a Growth Mindset. Thriving youth with FASD were described as seeing themselves capable of growth and having a positive sense of their ability to work hard to achieve their goals, even amidst challenges. "They need to see themselves as successful," said Elaine. "As in, yes I can do it. I will encounter failure, I will encounter struggle, but I can do this."

Several youth spoke about having a positive sense of their ability to accomplish their goals. Alanis said, “Sometimes I’ll just be there struggling and struggling. But I’ll get it done. I know I will. To the best of my ability.” Jade agreed, “I think that having to deal with different challenges, both mental illness and FASD, have made me stronger. Having to do a daily battle with my mind and day-to-day life. I’ve proved to myself how much I can do. I can push my limits of what I maybe thought I couldn’t do in the past.”

Feeling capable of working through challenges helps foster persistence and movement towards goals. Youth believed that they had the ability, so long as they worked hard, to accomplish their goals; this helped them to “never give up.” Alanis advised, “Just like in math, everything in life has an answer. Sometimes you just have to work a little hard to find it.” Ethan added, “There are always ways around challenges… No matter what you have, you can do anything, even if it takes an extra step or two… If you put your mind to it, you can do it… Never give up or say, ‘I can’t,’ even if sometimes you think you can’t.”

Feeling Happy

Participants described a thriving youth with FASD as one who is generally experiencing happiness. Many described happiness as the ultimate expression of a thriving trajectory; thriving in other areas is less meaningful if subjective well-being is compromised. “For me, happiness is number one,” Carla said. “Nothing else really matters if you’re not happy.” When asked how she knew her four young adult children with FASD were thriving, Beverley said, “I don’t know that I would like them to be anywhere else than where they are now. They are *happy* with their lives.” While she noted that it pleases her that her children are all employed, she said, “If they weren’t happy doing it as well? It would still be success, but a different kind of success.” Youth noted that they felt they were thriving because they were feeling happy about their day-to-day lives.

Ethan said he would recommend others with FASD to "do things that make you happy." To thrive, youth do not need to be "happy about their whole life," as Beverley said, but "happy about something." Alanis said, "I know that life won't always be happy, because that's life! But I see myself as mostly happy." The happiness associated with thriving is achievable and can be found "within each day." Violet said she always "dreamed" her children would be able to find joy in their everyday life. She said her son will call her to excitedly update her about his day: "I hear these statements of success from him that are not just statements, they are *expressions*… the joy in his voice, the satisfaction in his voice. The pleasure he is taking in life… These are the kinds of statements you dream that your children will be able to share with you."

Contextual Qualities That Support Thriving

Participants strongly emphasized the role of environmental support in fostering the development of the individual thriving qualities discussed above. Four inter-related themes emerged. First, the idea that *context matters*: it provides a foundation for thriving to occur. The subsequent three themes, *affirming youth, understanding youth,* and *responsive to youth's individual needs* describe key aspects of context that support youth thriving.

Context Matters

All participants were clear that *context matters*: relational and environmental support from adults in key developmental contexts (e.g., home, school, community) was seen as necessary to support thriving. Relational and environmental supports were viewed as *foundational* in that they needed to be present in the developmental period for thriving to later occur. Supports also needed to be ongoing and *grow with individuals* into adulthood.

Establishment of a Foundation of Support. Participants described relational and environmental supports as providing a strong foundation that makes thriving possible.

Relationships were seen as a particularly potent contextual element that helped youth to thrive. "Having supportive people around you will help you to be successful no matter who you are," said Carla. Thriving youth said they were supported by a network of relationships that extended from childhood into adulthood. Alanis said that "having a support system" made the difference between her and "other people [she] knows with FASD who have gotten into stuff that's not so good." Jade felt "having a lot of support" from her "mom, boyfriend, and family" made "all the difference." Jade said she saw differences between herself and her friends with FASD who were not doing as well: "Not everybody has had the support that I have." Although participants spoke about the importance of having a solid base of relational supports, many noted that youth with FASD can benefit from having "even one positive person" in their life. "It doesn't have to be a lot," said both Mary and Angie. Of the many adults with FASD she has worked with, Beverley noted, "I can't say that I've seen an individual who has FASD be successful without having at least one supportive relationship."

Participants also spoke to building a foundation of more broad-based environmental support through access to supportive agencies, services, and programs. Beverley said she could see "huge differences in the pathways" of adults with FASD with and without support, noting that thriving appeared to be "truly determined by the support in their lives." She said, "That is where we see the difference… even if it's agency support and not family." Elaine said, "I'd love to put [Ethan] up there and have everybody see. See! If we support people with FASD, it's possible that they become successful people."

Supports That Grow With Individuals. Although youth and caregivers indicated that receiving support in the developmental years was a foundational element that supported thriving, participants also noted that youth needed ongoing support into adulthood in order to thrive.

Caregivers noted that these supports cross multiple systems, including publicly funded community resources such as FASD mentorship programs and parenting programs, access to supported living and employment opportunities, and government financial assistance for persons with disabilities. All youth participants had accessed some or all of these resources in addition to ongoing relational support into adulthood.

Participants noted that receiving support into adulthood can help youth stay on healthy paths and move toward a positive future; continue to develop competency and autonomy; build connection; and participate meaningfully. Angie said that of the 20-plus foster children she had raised with FASD, only two had fallen into less healthy trajectories like addiction or criminality. They were the only two youth that did not receive ongoing support into adulthood "because they had higher IQs and they couldn't qualify for the support." Angie felt that both Alanis and Alicia "would not be in the same place if they hadn't gotten the support" into adulthood, particularly with independent living and financial assistance.

As an extended example, Alanis was able to pursue a thriving trajectory in young adulthood through the help of ongoing relational and environmental support that extended from a foundation built in childhood. To pursue college, Alanis had to move from a small town to the city, which Angie was sure Alanis would not be able to "handle safely on her own." With government financial assistance, Alanis was able to rent a suite in a former foster family member's basement and receive help with the practicalities of life – enrolling in school, learning to take public transit, managing money, seeking health care. This allowed Alanis to feel competent and autonomous, participate in life, and move toward her goals. Alanis said, "If I have a question… like what do I do if I'm sick? How do I find a doctor? How do I get my birth

control? I didn't know how to do any of those things at the time. I can get help. She'll tell me the steps… She helped me with enrolling in school and figuring out the loan."

Similarly, Violet described how ensuring her son had a wealth of support in his transition to adulthood has been key to helping him navigate toward situations that allow him to thrive and shine in independent living and employment:

> He is always supported. He always has another adult with him who is able to see ahead where the bumps might be and give him some direction so that… he's able to avoid situations that might present difficulty and he's able to steer toward situations that he can manage really well.

And Beverley said that she attributes a "big part" of her four children's ongoing success and thriving to her and her husband "staying in their lives" after they turned 18. When adults with FASD struggle to thrive "it's not because they can't," Beverly said. "It's because the support systems are not in place. [My kids] will always need support, but so do typically developing adult children. It just might look a little bit different. It might be a little more intensive at times."

Affirming Youth

Youth with FASD are supported to thrive when adults in key contexts provide positive regard and affirmation to youth. According to caregivers, having positive regard for youth and communicating this to them fosters the development of individual markers of thriving, such as an integrated identity. Violet said, "Whether we consider them and their successes to be valid or important… that is communicated to our children… overt or subtle." In other words, youth "self-perception of success is linked to others' perception of their success." Beverley said, "Kids who are supported in their homes – it doesn't matter what level of brain damage they have. When they are in a positive environment, they will tell you how successful they are. Because they have

that knowledge in themselves." Caregivers believed that thriving with FASD is supported by youth having significant adults in their lives who "value and appreciate" them, as Violet said, and who actively and intentionally communicate this regard to youth by "verbalizing, sharing, and recognizing in a really authentic way" all the things youth have to offer. This helps youth develop "a continuing and ongoing understanding of who they are as people and why that's really important; why the world is a better place because they are in it."

Participants also felt that the development of meaningful participation and the drive to move toward a positive future was supported by key adults communicating positive regard to youth. When asked how she was able to overcome her fear of going back to school to pursue her GED, Jade said, "A lot of it was just my mom saying how proud she is of me." Jade said that important others in her life – her family, boyfriend, and employer – have also supported her to thrive by "praising me when I do positive things." Beverley described her son as holding a job for the longest he's ever been able because "He has a supportive supervisor who tells him, 'You're a good worker.' And that's what he needs. Someone to say, 'You're good at this.'" "All kids like to be told when they're doing good," said Angie, "but fetal alcohol kids need that especially."

Understanding Youth

Caregivers believed that youth with FASD are supported to thrive when adults in key contexts understand them as individuals. This means understanding that youth have individual needs that must be contextualized within their environments, and that youth are capable of growth. The power of adult understanding to facilitate youth thriving is discussed through two subthemes: *understanding individual needs in context,* and *encouragement to grow.*

Understanding Individual Needs in Context. In order to thrive, youth with FASD needed adults in key contexts to understand them at an individual level, as well as from an FASD-informed perspective. They also required their behaviours to be understood as reflecting needs not being adequately addressed by the environment.

Caregivers collectively recognized the importance of gaining a "really thorough understanding" of where each and every youth "are at individually, and what their unique needs are," as Violet put it. Even though youth "histories may be similar" in terms of the etiology of their challenges, caregivers noted that each of their children were extremely different. "Their brain injury clearly affects each of them differently," said Violet. "So we can't do the same for everybody. We have to do what's best for everybody." Understanding youth's unique individual needs is essential to providing a customized response (described in the next theme). It also provides a framework for understanding individual markers of thriving. In addition to understanding each child's individual needs within the context of their environment, caregivers also felt, as Carla said, that any adults supporting youth "have to have a good understanding of FASD to be even remotely successful." Elaine felt that one reason Ethan is now thriving is that everyone who "contributed pieces to make him a success" – from his teachers to his employers – had been "knowledgeable" about FASD and had also "really understood him."

Caregivers described coming to understand youth's behaviours as reflecting unmet "needs" rather than as inherent challenges. Beverley said that when she was raising her first two children, she had understood them from the perspective of "behavioural modification, that everything was intentional." She felt her children were supported to thrive when she was able to shift her understanding. "Looking back… none of it was intentional. It was reacting to life… I began learning more about the disability… And I started paying attention – so if there was a

behaviour happening, I wasn't looking at what my son was doing, I was looking at what the surroundings were doing to him."

Encouragement to Grow. Caregivers believed that youth thriving was supported when adults in key contexts understood that youth are capable of growth, and that they need encouragement to grow through growth-oriented expectations.

Caregivers believed that youth were capable of growth and change. Angie described returning from an FASD-informed parenting workshop feeling that there was "no hope." Her husband said with great certainty, "That is not true. They will change." After raising over 20 children with FASD to what she would consider successful adulthood, Angie said, "We never looked back." Mary said that in supporting her children to thrive, it was critical to understand that "They have a brain like anyone else. Their brain can grow, they can develop, they have potential." Beverley said she truly believed that for her kids, "The possibilities are infinite."

Holding this belief helped parents to "not lose hope" and to set expectations that encouraged youth to ultimately express markers of thriving such as competence and autonomy, meaningful participation, and moving toward a positive future. Caregivers described holding expectations set within the boundaries of what was individually and contextually reasonable; seeing the spaces youth could grow into instead of only looking to what was not possible. "I really needed to embrace what could be," Violet said. "That is where the hope is. And that is where you can make the most of what *is* rather than being discouraged or limited by the challenges… Once you understand the realities, you can then absolutely make the most of the opportunities." Encouraging youth to grow required caregivers to see growth as a process instead of "looking to the end," as Beverley said. "I went from, 'This is where you're going to get'… to 'how far can you go?' And not, 'This is where the end is.' Our expectation is not that you are

going to be something or achieve a specific outcome. It's to find out what you can do. We say, 'let's journey and see where you go.'" Caregivers described an openness and trust in their children's capacity for growth, and a commitment to be there with them along the way. As Beverley said, "I don't know where we're going, but we're going to get there, wherever it is. Wherever they need to go, that's where I'm going."

Youth perceived adults' understanding of their capacity for growth through adult encouragement. Jade attributed her current and growing sense of competence and autonomy, as well as the progress she was making in working toward her future goals, to family members, her boyfriend, and her employer "encouraging me to achieve my goals." Alanis and Ethan both spoke about feeling encouraged to pursue their goals by having teachers who communicated to them that they believed in their ability to grow and succeed. Ethan said of his teachers in technical college, "They see the end of the road for me. They really think I can do it."

Responsive to Youth's Individual Needs

Caregivers felt that youth with FASD are supported to thrive when adults in key contexts respond to youth's individual needs by adapting the environment to provide individually-appropriate environmental support and accommodation.

Based on an understanding that youth challenges reflected unmet needs in the environment and that youth were capable of growth, caregivers believed that supporting thriving required responding to individual needs by "building a customized environment," as Violet said, rather than trying to "force" youth to adapt. As Beverley said, "When we change the environment; when we put things in place and teach others, that changes our children's abilities." Several caregivers used the metaphor of needing to respond to the challenges associated with FASD in a way that reflected that individuals do not need to change; their environments do. "If

he was in a wheelchair, we wouldn't say… Well he's just going to have to walk, because that's what everybody does," explained Violet. "We would say: No. We need to make sure there's a wheelchair, or a walker, or a lift." The same goes for youth with FASD: "We need to adapt the environment to recognize where the challenges are so that we support him in being able to maximize his capacities and being able to give the gift that he has to give the world."

Caregivers reported seeing monumental changes in youth once they were able to decode the puzzle of how to adapt the environment. "Once we were successful in doing that, we saw really good things happening for him," Violet said. Mary agreed, "The experience of trying to change their environment has helped." Violet provided an eloquent example:

> As [my son] got older and the demands on him got higher, just by virtue of the school environment that he was in, we scaled back our requirements of him at home. So at age 9 he was doing all of his own laundry… and then he really began to struggle [in school]… So at that point we started changing what our expectations were at home. By the age of 14, he was doing no chores at home at all. He couldn't… And we knew that once we had made it through school and we had him in a fully customized adult living environment, we would be able to bring those things back online for him… By the time we got to Grade 12, we weren't even asking him to choose his own clothes for the day… it was a cost he couldn't afford to pay because he would then go to school with less resources to manage his day… If you think of it like a bank account, the withdrawals that were being required outside the home got bigger and bigger. The resources stayed the same, but the expectations got bigger and bigger. So we very consciously made the withdrawals that we were expecting at home smaller and smaller.

All caregivers and most youth described school as being a key developmental context in which youth required an appropriately responsive environment in order to thrive. According to participants, receiving individually-responsive support in school was a major factor in supporting connection, competence, participation, integrated identity, moving toward, and happiness. All youth participants had been in modified programs throughout school, but reported different experiences with these programs being able to meet their individualized needs. Elaine noted that Ethan thrived "being in a class of 12" because he "got a lot of individual attention" which was "really good for him." For Mary's son, "as soon as they put him in the [Knowledge & Employability] program and he had an aide that was one-on-one with him" he went from having behavioural issues that resulted in criminal charges to "graduating with honors." He had enough "people around him to help him keep focused." He was focused on school and he was "happier."

Discussion

In this study, I explored what it means to thrive with FASD by eliciting the perspectives of those living this experience: young people with FASD and their caregivers. Guided by PYD and relational-developmental systems theory, I learned that young people with FASD *can* and *do* thrive. Overall, participants described thriving as an individualized process that incorporates both individual and contextual factors. To thrive with FASD is to fully participate in a life that is happy and filled with meaningful connection to others. Thriving youth with FASD feel like they are acquiring the skills to manage themselves and their environments in order to live their lives under their own power and direction. They have found ways to use their strengths and have an integrated and overall positive sense of themselves. They can envision a healthy future for themselves, one they are interested in and feel capable of achieving. Their thriving is undergirded by supportive relationships and environmental supports that extend from childhood

into adulthood. This broadly aligns with a PYD and relational-developmental systems theory of thriving, suggesting that thriving is generally an inclusive, generous, and growth-oriented construct. Although many aspects of thriving with FASD were similar to the thriving literature, differences also emerged, as set out below.

Individual Markers of Thriving

Thriving with FASD reflects the growth and expression of several individual qualities that mark a young person as being on a path to success. At a broad level, these qualities are similar to those described in the PYD literature. However, the specifics of some of these qualities and their relative importance in a thriving trajectory differ.

Thriving youth with FASD experience meaningful *connection to others*. This is unsurprising; relational connection is a basic human need that is not just essential for survival and resilience, but also to thriving and well-being (Arnold, 2018; Bowers et al., 2015). However, this finding offers a new perspective on the importance of relational connection for youth with FASD specifically. Much research has documented how *providing* relational support and connection to youth at-risk or those with disabilities is critical, but few have tried to understand how youth's subjective *perception* of connection, love, and stability relates to the experience of success, thriving, or well-being. Feeling connected mattered deeply to youth with FASD. Regardless of past history, establishing a sense of love and stability by emerging adulthood was viewed as thriving. Thriving through connection conveyed a sense of ongoing growth: youth believed these loving, stable connections would continue through their lifespan, growing to form new connections with others in ways that are appropriate for their age and stage of life. To thrive with FASD also means that youth feel as though they can contribute to relationships and feel that their contributions are valued. Through this, youth experience a sense of belonging. Although

this study was guided by PYD theory, self-determination theory (Deci & Ryan, 2000) has been applied to thriving, albeit in occupational settings (e.g., Spreitzer & Porath, 2014), and supports these findings as well. Self-determination theory identifies *relatedness* as being one of three key nutrients for human growth and thriving (Deci & Ryan, 2000, 2008). Relatedness describes the need to feel connected to others, fulfillment of attachment needs, and a sense of belonging.

To thrive with FASD is also to experience *competence and autonomy.* For youth with FASD, building skills fostered a sense of mastery over one's external environment and internal states (i.e., self-regulation). This permitted youth a sense of control and agency in their lives: they felt self-directed and able to do things for themselves. Building competence and autonomy are central developmental tasks, as is the development of self-regulation. In the PYD literature, competence is defined variously as school success (including school grades, attendance, and test scores; Benson & Scales, 2009; Bowers et al., 2010), feeling confident about one's ability to perform tasks, and having a positive view of one's actions in various areas including academics (Benson & Scales, 2009). Self-regulation is typically framed as behavioural competence, self-control (Bowers et al., 2010), and intentional self-regulation (Benson & Scales, 2009; King et al., 2005). It is seen as a marker of thriving because it allows individuals to effectively respond to their environments and regulate their behaviour in the direction of valued outcomes (Lerner, Lerner, Bowers, et al., 2011). In populations with developmental disabilities, achievement of competence and autonomy goals are often a focus of intervention and are seen as markers of success. Although youth with FASD and caregivers felt that accomplishing competency goals was important, they emphasized the importance of the subjective experience of mastery and autonomy that gaining competence conveyed. Even if youth required support, being able to experience autonomy by making their own choices, decisions, and acting as independent agents

in their lives was prized. Success in these areas was defined individually based on what each youth found relevant and achievable.

Self-determination theory may help reconcile the tension between outcome and process that is seen within the theme of competence and autonomy. In addition to relatedness, self-determination theory proposes that the need for competence and autonomy drive human growth (Deci & Ryan, 2000, 2008). Wehmeyer and colleagues (e.g., Wehmeyer, 2005; Wehmeyer & Little, 2013) have proposed a functional model of self-determination that focuses on self-determined behaviour, defined as "volitional actions that enable one to act as the primary causal agent in one's life and to maintain or improve one's quality of life" (Wehmeyer, 2005, p. 117). Thus, it is not specific behaviours or outcomes that determine self-determination, but the function of behaviours: whether a behaviour allows individuals to act autonomously and in a self-regulated, "self-realizing," and "psychologically empowered" way (Wehmeyer & Little, 2013, p. 6). Viewed from this lens, youth with FASD thrive when they are able to become, as Seligman and Csikszentmihalyi (2000) wrote, "decision makers with choices, preferences, and the possibility of becoming masterful, efficacious" (p. 8).

Youth with FASD who are thriving are *participating meaningfully* in life. They are engaging in occupations and interests that constructively occupy their time, that actively include them in life, and that are a vehicle through which to channel strengths. PYD views participation in terms of *purpose*, or "engagement in pursuits that serve the common welfare and make meaningful contribution to communities" (Lerner et al., 2015, p. 8) and *contribution*, which involves active participation in life through leadership and efforts to make a difference (Bowers et al., 2010). To an extent, making "meaningful" contributions, having one's actions construed as "making a difference," and having the power and status to enter leadership roles requires an

individual to claim space in society that is not typically allocated to individuals with developmental disabilities. It requires communities to value and respect every individual's abilities and contributions and view them as meaningful. This represents a complex intersection between societal values of purpose, contribution, and participation with pervasive stigma – for example, that individuals with disabilities like FASD do not contribute or participate as much as they take (Choate & Badry, 2019; Corrigan et al., 2019). For definitions of thriving to truly include *everyone,* as PYD claims, there needs to be flexibility in understanding the range of ways in which all people participate, contribute, and find purpose.

A key way youth with FASD spoke about participating is by capitalizing on their strengths. When youth are supported to find and use their strengths, both youth and those around them have the opportunity to view youth's strengths and contributions as meaningful, important, and valued. The PYD model claims that "all young people have strengths that may be capitalized on to promote thriving" (Lerner et al., 2011, p. 1108). Benson and Scales (2009) describe these strengths or self-identified interests and passions as *sparks*, which are pursued through intrinsic motivation. Youth with FASD reported a different quality of spark. Although thriving youth with FASD did speak about pursuing interests, passions, and challenges for their own sake, many found meaning in finding ways to use their talents instrumentally to pursue individually-valued concrete goals such as working to make money. Instrumentally-motivated behaviour is often implied to be inferior to intrinsic motivation in the context of thriving (e.g., Brown et al., 2017). However, research has shown that when tasks or goals are perceived as meaningful (which concrete, instrumental goals clearly were to youth) people tend to show more signs of thriving (e.g., Spreitzer et al., 2005). For youth with FASD, it could be more valuable to look at what interests and goals energize them and allow them to use their strengths, regardless of whether or

not the source of energy is intrinsic or extrinsic. A unique element of capitalizing on strengths in FASD is transforming challenges into assets. Other qualitative research, such as a case study by Brenna and colleagues (2017), have reported a similar phenomenon of noting "ability within disability" (p. 226) among youth with FASD.

According to participants, youth with FASD who are thriving are developing an *integrated identity.* In typical development, identity formation is conceptualized as an ongoing task that begins in adolescence and is essential to "life-long psychosocial well-being and thriving" (Arnold, 2017, p. 1). There are many theories of identity development. Those that fit with PYD emphasize a process of individual exploration and commitment that is affected by an individual's social ecology (Crocetti, 2017; Kroger et al., 2010; Marcia, 1980). For individuals with developmental disabilities, an important part of identity formation is developing a sense of self that positively integrates the experience of disability. This process usually involves self-understanding of strengths and difficulties, finding ways to cope with limitations, and accepting ones' differences (Olney & Kim, 2001). An integrated disability identity is believed to enable individuals to succeed (Dunn & Burcaw, 2013). Thriving youth with FASD have integrated an awareness of their strengths and weaknesses into their identity. They have found ways to understand their limitations and challenges as just one aspect of who they are. This supports findings from other qualitative studies among youth with FASD (e.g., Brenna et al., 2017; Knorr & McIntyre, 2016), suggesting that supporting youth with FASD to develop awareness of their strengths and challenges and integrating FASD into a positive identity may help youth to thrive. Thriving in typical development reflects an animated and dynamic process of growth; of "moving toward a hopeful future" (Benson & Scales, 2009, p. 91). Thriving with FASD was also characterized by *moving toward.* To thrive with FASD is for youth to see a future for themselves

that matters to them. They set goals and make choices that move them along a path toward those goals, allowing them to "flower into the kinds of persons who do not just avoid problems and pathologies, but who embrace life and make use of their own special gifts" (Benson & Scales, 2009, p. 91). This finding strongly differentiates thriving with FASD from being simply resilient: youth are not just avoiding negative outcomes, but are directing their lives down healthy paths filled with hope and potential.

According to Larson (2006), PYD is "a process in which young people's capacity for being motivated by challenge energizes their active engagement in development" (p. 677). Similarly, thriving with FASD reflects persisting through challenges, and even deriving energy and motivation from confronting challenges. Persistence has been implicated as contributing to successful outcomes in other qualitative studies of youth with FASD (e.g., Brenna et al., 2016). Youth with FASD who are thriving also believe in their ability to navigate toward goals they have envisioned for themselves, so long as they worked hard and persevered through challenges. This is similar to the PYD thriving indicator of *confidence* (Lerner et al., 2015), but also reflects a growth mindset (Dweck, 2006). Mindset refers to fundamental beliefs about whether personal qualities (e.g., intelligence, personality, emotions, behaviour) in different domains can change. Holding a growth mindset, i.e., perceiving certain personal traits as malleable versus fixed, has been linked to a number of positive educational and psychosocial outcomes (e.g., Blackwell et al., 2007; Burnette et al., 2013) as well as perseverance and effort (Mrazek et al., 2018). Mindset has been minimally studied in populations with developmental disabilities, other than to note that students with learning difficulties or intellectual disabilities may be more likely to have a fixed sense of their intelligence and behaviour (e.g., Baird et al., 2009; Verberg et al., 2019). Yet,

mindset can be learned. The results of this study suggest that when youth are able to develop self-beliefs and behaviours consistent with a growth mindset, they thrive.

Finally, participants felt that to thrive with FASD is to experience *happiness* and positive emotions. In line with findings from the broader PYD literature (e.g., Benson & Scales, 2009; Lerner et al., 2011), thriving youth are those who express positive emotionality (happiness, positivity, optimism) and feel good about their lives. Relatively few have studied happiness and subjective well-being among those with developmental disabilities. Most research in this area has focused on the happiness and well-being of those who support individuals with disabilities (Shogren, 2013). Some researchers have lobbied to include happiness as a key outcome variable in intervention research among those with disabilities (e.g., Carr, 2007). However, actualizing this seems to have been hindered by several factors, including framing quality of life based on normative outcomes (e.g., independent living, employment; Grove et al., 2018) and difficulty developing methods to assess happiness and well-being among those with cognitive differences (Shogren, 2013). Understanding the experiences of happiness and life satisfaction among individuals with FASD and the factors that contribute to it may help encourage thriving.

Contextual Qualities That Support Thriving

According to PYD and relational-developmental systems theory, thriving results from aligning individual markers of thriving with relational and contextual factors that promote their development (Benson & Scales, 2009; Lerner et al., 2015). Participants were clear that receiving ongoing relational and environmental support was foundational in the development of thriving with FASD. Indeed, supportive relationships fortify healthy development in general, as well as potentiate thriving (Arnold, 2018; Bowers et al., 2015; Roehlkepartain et al., 2017; Scales et al., 2011). Relational support plays an enhanced role in situations of adversity (Masten & Cicchetti,

2016) and for people with developmental disabilities, including FASD (e.g., Duquette et al., 2006; Knorr & McIntyre, 2016). It is within the context of these relationships that youth experience a sense of connection; develop competency and autonomy; integrate a positive identity; and are supported to find and use their strengths, set goals, and persist toward them. Although receiving support nurtures thriving in typical development (Benson & Scales, 2009), environmental support may play an even greater role for those with developmental disabilities. The lifespan environmental support needs of individuals with FASD across multiple systems of care have been well-documented (Millians, 2015), and youth and caregivers in this study argued that it is possible for youth with FASD to do well when adequately supported. Their voices are joined by other research findings that have suggested that providing adequate environmental support to youth with FASD is related to academic success (including better school attendance, self-esteem, self-understanding, and self-acceptance; Millar et al., 2017), academic persistence (Duquette et al., 2006; Job et al., 2013), and goal achievement (e.g., Denys et al., 2011).

Participants also expanded on the qualities of relational and environmental support that were essential to promoting thriving trajectories. First, *affirmation* of youth by key adults was seen as vitally important. The positive regard communicated to youth within these relationships may provide a foundation for youth to begin to form a positive sense of themselves. As Niemiec and Ryan (2009) wrote, "People tend to internalize and accept as their own the values and practices of those to whom they feel or want to feel connected and from contexts in which they experience a sense of belonging" (p. 139).

Second, participants emphasized the importance of key adults deeply *understanding* youth with FASD at multiple levels: individually; within the context of FASD; and within the context of youth's environments. It is important that key adults understand that youth with FASD

are capable of growth and change. When adults believe this, they can set appropriate expectations for youth. This creates positive pressure to grow and thrive (e.g., Benson & Scales, 2009; Roehlkepartain et al., 2017). Further, when key adults deeply understand and hold growth mindsets for youth, youth are encouraged to develop these beliefs and attitudes about themselves. However, some studies of caregivers of youth with FASD have found that expectations for growth can be difficult to navigate. When Brown and colleagues (2019) asked caregivers of youth with FASD what kind of future they expected for their children, responses generally clustered around themes of fear; expectations for ongoing challenges and serious problems; and a belief that youth will always need a high degree of support to function even somewhat competently. These fears do map on to a fairly substantial literature documenting numerous problems in childhood that may worsen with age (e.g., Rangmar et al., 2015) and may require a high degree of support into adulthood (e.g., DeJoseph, 2011). However, qualitative investigations such as this study illuminate trajectories that may be characterized by times of challenge, enhanced need for support, and a great deal of effort on the part of youth, caregivers, and environmental systems; but that are also characterized by incredible successes and joys when expectations are flexibly adjusted, remain hopeful for growth, and work in tandem with an individualized and customized environment. Further, even though several quantitative studies examining outcome trajectories report that the "majority" of adults with FASD lag significantly behind their peers, large proportions (e.g., one-third to one-half) of participants in these studies show growth through attaining independent living, employment, high school graduation, and college attendance (Lynch et al., 2015; Rangmar et al., 2015).

Participants also highlighted the need for a responsive environment: thriving can be supported by adapting the environment to meet individual needs. This standpoint is supported by

the strengths-based disability literature (Buntinx, 2013), which views disability not as "a deficit that resides within a person, but rather as an interaction between personal capacities and environmental demands" (Shogren, 2013, p. 2). Although PYD does not reference attending to unique individual needs in the context of disability, the literature does emphasize that thriving occurs partially as a result of supportive contexts, and that youth thrive when their environments are responsive to their needs and their stage of development (Eccles & Roeser, 2009; Lerner et al., 2015). Viewing the challenges that are part of the experience of FASD as reflecting an incompatibility with environmental demands and supports rather than as an individual flaw is fundamentally hopeful and action-oriented. Changing aspects of the environment will almost always be easier than attempting to directly change individual qualities.

An Integrated Understanding of Thriving With FASD

The findings of this study provide a starting point for important individual qualities and contextual supports to consider when conceptualizing thriving with FASD. However, thriving is not one-size-fits-all. The specifics of what thriving *looks like* for any individual with FASD must be customized to each individual's unique abilities, strengths, and challenges, and how these interact with an individual's environment. Research has shown that, at a group level, FASD is characterized by a particularly complex and diverse set of cognitive and behavioural challenges compared to other developmental disabilities (e.g., Greenbaum et al., 2009). There is also significant variability in the profiles of strengths and weaknesses between individuals within FASD, as well as within individuals. Youth participants in this study were diverse in abilities, and all were viewed as thriving. In addition, participants believed anyone with FASD was capable of thriving. Therefore, to thrive with FASD is not to thrive in relation to others. When conceptualizing success among individuals with FASD, it is important to go beyond normative

comparisons and consider how individuals are doing in relation to themselves, their capacities, and their subjective experiences. Individuals' definitions of thriving are likely to shift over time as they grow and develop, as their environments change, and as supportive others in their environment come to understand youth better and youth come to understand themselves better. Thus, thriving with FASD is also an ongoing process.

Thriving with FASD can be understood as an individualized process of experiencing, moving toward, and growing. There is disagreement in the broader thriving literature about whether thriving is a process, an outcome, or both. Even within process-focused PYD-informed research, there is an implicit assumption that to be thriving, one is accomplishing specific tasks (e.g., graduating, securing leadership roles, volunteering). Within special education settings and the developmental disabilities literature, success is also often measured by milestones such as high school graduation, getting a job, and achieving independence. Participants in this study did care about the achievement of certain outcomes and accomplishments, and highlighted the importance of avoiding certain outcomes. Yet, overall, participants prioritized the *journey* toward thriving. That is, thriving is less about accomplishing specific goals and more about what goals – and the journey toward them – represent. For example, when you have FASD, the journey of moving toward school completion can be characterized by the same thriving qualities as receiving a diploma: showing persistence and motivation; feeling competent and autonomous; feeling positive about oneself; participating. Achieving work is less about the specifics of job title, salary, and status; rather, the job represents growth and energy being put into participating, using strengths to overcome challenges, developing connections with others, and through this all, developing a positive identity and a sense that you have a place and are valued.

Part of viewing thriving as an ongoing process is to understand that thriving is not all-or-nothing. Thriving with FASD does not mean youth must demonstrate every marker of thriving every day. According to participants, it is possible for a youth to be thriving or on a path toward thriving even if they stumble, are struggling in some areas of their lives but not others, or if they have not accomplished specific milestones. Youth may be more or less thriving-oriented at different points in their lives, and may be struggling in one area while thriving in another.

Limitations

This project presents the perspectives of a small number of youth and young adults with FASD and their caregivers. I have provided a rich description of participants and their ideas, included a diversity of participants from across the FASD spectrum, interviewed youth with FASD and caregivers, and encouraged caregivers speak about their experience raising children with FASD beyond the youth participants. Through this, I believe that many youth with FASD, their caregivers, and other key figures in their lives will be able to see themselves, their children, their students, or clients within these themes. Nonetheless, it is important to recognize that while I had hoped to speak with youth that were thriving and those that were not, the sample ultimately consisted of youth who reported that they were in the process of thriving. Although some caregivers spoke about their children with FASD that they would not consider to be currently thriving, these results do not provide a clear picture of the low points or transitions in and out of thriving. Additionally, all youth participants were recruited alongside their caregivers, with whom they had long-term and ongoing relationships. This is not necessarily typical of all youth and young adults with FASD. Thus, thriving may look different for youth with FASD who do not have consistent, stable relationships with caregiving figures.

Like all qualitative research, this study elicited the subjective viewpoints of individuals intimately familiar with a phenomenon. All self-report research comes with limitations. Self-report can be affected by many variables, including social desirability. Given the subject matter and the fact that individuals with FASD face persistent marginalization, it is possible that participants felt consciously or subconsciously drawn to idealism. However, even without interviewer prompting, all participant narratives included balanced discussions of strengths and challenges. Further, the resultant markers and supporters of thriving appeared to be grounded in achievable and individualized attitudes, behaviours, and goals.

Including youth perspectives was important to understanding this phenomenon. Youth participants ranged broadly in their level of cognitive functioning and expressive and receptive language ability. Yet, all participants spoke profoundly about their lived experience and contributed enormously to understanding thriving. However, some youth were not able to express themselves as fully as others, both in content and level of abstraction. Including the perspectives of caregivers helped triangulate and expand upon youth's ideas. However, future studies may wish to include other methods of data collection, such as drawing or Photovoice (Wang & Burris, 1997), which may supplement youth's ability to express themselves.

Future Directions

There is a fairly good understanding in the FASD literature that connection with others and working toward building skills and independence are important to avoiding negative outcomes. Less is understood about the subjective experience of connection for individuals with FASD, and how meeting needs for connection, competence, and autonomy may motivate growth and ultimately, thriving. An exciting potential avenue for future research could be to incorporate a framework of self-determination to examine how young people with FASD experience

autonomous motivation and positive growth. Capitalizing on strengths and interests was found to support meaningful participation. Future studies could investigate how identifying and pursuing sparks affect youth's subjective well-being, participation, connection with others, development of self-regulation, and formation of a positive identity. Going beyond looking at interests, skills, and passions to examine character strengths – qualities that are core to an individual's identity – has also been suggested as important to understanding how to help individuals thrive in everyday life (see Niemiec et al., 2017). Another avenue for future research would be to investigate happiness and subjective well-being. For example, how individuals with FASD define and experience happiness and life satisfaction, how this relates to quality of life, and how well-being is fostered. I encourage future researchers to continue to ensure that individuals with FASD are given the opportunity to share and define their experiences, successes, and needs through research that is collaborative and responsive. Further research in this area would benefit from using clearly articulated theoretical frameworks (e.g., PYD, self-determination theory, subjective well-being, quality of life, social-ecological models of disability).

Final Thoughts: Supporting Youth With FASD to Thrive

People are not born with competence, an integrated identity, subjective well-being, or many other markers of thriving; nor can they be given these things. However, they can be supported to develop these qualities by caring adults in multiple developmental contexts. Connection with youth is built over time. An important part of experiencing connection is for youth to feel like they belong and are an important part of something. Encouraging youth with FASD to participate in activities, clubs, teams, and leadership opportunities that speak to their interests and strengths could be one possible avenue. Youth can also feel connected when they have the opportunity to contribute. Possibilities could include volunteering (e.g., mentoring

younger people with FASD, coaching, teaching a skill/creative pursuit, contributing to newsletters), getting involved in social justice issues (e.g., disability rights), or even participating in research such as this. Adults can support youth to develop competence, a positive sense of self and abilities, and a mindset of growth and persistence by allowing youth to take on tasks where they can practice and succeed; encourage youth to take safe risks and confront failure; scaffold decision-making and problem-solving; notice improvements and growth; emphasize effort, attitude, and process more than accomplishments; and help youth see their own gifts and talents. Youth with FASD should be encouraged and supported to pursue goals that allow them to participate and connect with others; that they enjoy; and that use their strengths, interests, or even hidden strengths. Overall, those supporting youth with FASD should hold individualized, growth-oriented, and flexible expectations for in(ter)dependence, education, occupation and participation in life that is meaningful to youth and others around them. Those supporting youth can also acknowledge that multiple support systems must be leveraged to accomplish these goals, as well as the interaction between individual and environmental resources.

This study has shown that it is possible for youth with FASD to thrive. Indeed, at a broad level, the qualities that mark a thriving individual with FASD are those that describe anyone who is thriving. Thriving is individual, but it is also a joint human experience of connecting meaningfully with others; participating fully in life; using our unique gifts and strengths; feeling as though we have mastered ourselves and the world around us; feeling a sense of subjective well-being; and being constantly driven to grow and move forward. Given a supportive social ecosystem that nurtures youth through affirmation, understanding, and responsiveness, the possibilities – as I was told – are limitless.

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Chapter 5: Conclusion

Fetal Alcohol Spectrum Disorder (FASD) is a life-long neurodevelopmental disorder. It has been widely recognized that individuals with FASD experience significant cognitive, learning, and behavioural challenges across the lifespan (Cook et al., 2016; Mattson et al., 2019). They are also at greater risk of experiencing postnatal adversity, which can negatively impact development and contribute to the myriad adverse outcomes associated with FASD (Kambeitz et al., 2019; McLachlan et al., 2015, 2020; Streissguth et al., 2004). Five decades of research has provided a good foundation to understand the difficulties associated with FASD. This has bolstered efforts to support individuals with FASD across multiple systems of care. However, there has been increasing recognition of the limitations of this deficit-perspective. Greater attention is now being given to recognizing the heterogeneity in symptoms and outcome trajectories among individuals with FASD through research that examines resilience, individual and systemic strengths, and individual and familial capacity for growth and change. Understanding the full complexity of FASD is required in order for research, policy, and clinical practice to adequately support individuals with FASD and their families across the lifespan.

The overarching goal of this manuscript-based dissertation was to contribute to an enhanced, balanced, and integrated understanding of FASD by exploring how individuals with FASD navigate toward health and optimal functioning. To do this, I investigated two strengths-focused, growth-oriented, and systemic phenomena among youth and young adults with FASD: resilience and thriving. In the following section, I briefly summarize the findings from Study 1 (Resilience and FASD) and Study 2 (Thriving with FASD). I then move into a deeper discussion and integration of key findings, exploring how the results of these studies add to the literature, inform clinical practice, and direct future research.

Study 1: Resilience and FASD

Existing FASD resilience research has been predominantly characterized by quantitative examinations of risk factors for poor outcomes, as well as protective factors that help individuals with FASD avoid negative outcomes (e.g., McLachlan et al., 2020; Streissguth et al., 2004). A handful of qualitative studies have also examined individual and contextual qualities associated with positive outcomes such as school persistence (e.g., Duquette et al., 2006), employment (e.g., Kapasi et al., 2019), and avoidance of criminal justice involvement (Currie et al., 2016). In Study 1, I sought to broaden our understanding of individual, relational, and contextual resilience resources present among a group of young people with FASD, and investigate how these resources relate to two important functional markers: emotional and behavioural functioning. The results of this quantitative study showed that youth with FASD and their caregivers reported youth to have lower contextual resources but similar relational resources to a typically-developing reference group on the Child and Youth Resilience Measure (CYRM). Caregivers and youth disagreed in their reporting of youth individual resources. Youth reported comparable individual resources to the typically-developing reference group, whereas caregivers reported youth to have fewer individual resources than a high-risk reference group. Resilience resources were not related to a measure of cumulative risk (ACE score) or individual factors such as age, sex, or IQ. However, early stability and early diagnosis were related to greater caregiver-reported relational and contextual resilience resources. Mental health symptomology in this sample was generally higher than the normative average, and adaptive functioning was generally lower than average. However, youth with higher individual resources were reported to have less mental health symptomology and better adaptive functioning. Higher contextual resources were also associated with better adaptive functioning.

Study 2: Thriving with FASD

To date, no researcher has asked what it would mean, at a broader level, to be successful with FASD beyond achievement of normative outcomes or avoidance of negative outcomes. Study 2 was a basic qualitative study guided by positive youth development and relational developmental systems theory. The purpose was to understand what it means to thrive (i.e., develop optimally) with FASD according to youth with FASD and caregivers. Overall, thriving with FASD was described as an individualized process of growth, expressed through the interaction of youth individual qualities with a supportive environment. Participants described six broad individual qualities of youth indicative of thriving with FASD. These six themes were: *connection to others*, *competence and autonomy*, *meaningful participation*, *integrated identity*, *moving toward*, and *feeling happy*. Participants also described qualities of the environment that supported the development of thriving, captured by four themes: *context matters*, *affirming youth*, *understanding youth*, and *responsive to youth's individual needs*. Themes were generally consistent with those described in the broader thriving literature (e.g., Benson & Scales, 2009). However, there were nuanced differences, which I will touch on in the next section.

Discussion and Integration of Key Findings

Importance of Relationships

In the broader resilience literature, caring relationships with adults are a potent source of resilience, especially for youth most at-risk (Masten & Cicchetti, 2016). Positive youth-adult relationships are also key facilitators of thriving (Bowers et al., 2015). It was clear from the findings of Study 1 and 2 that supporting the development of close, caring, stable relationships with key adults is also critical for youth with FASD.

In Study 1, participants reported a high level of relational resources. This may have been reflective of the sample, which was characterized by fairly long-term, stable relationships between youth and caregivers. Although relational resources were not associated with emotional

or behavioural functioning in this study, it has been theorized that relationships form a powerful basis for the development of other resilience resources through an ongoing interaction between individual youth, their relationships, and developmental contexts. The findings of Study 2 appeared to support this theory. Participants in Study 2 believed unequivocally that relational support was essential to thriving with FASD. Perhaps most important were caring relationships with caregivers that began in childhood and extended into adulthood, although participants also noted the importance of supportive relationships with family, romantic partners, teachers, and mentors. Specifically, relationships that provided affirmation, understanding, and encouragement were said to nourish many aspects of youth thriving, including the development of healthy and loving connections with others, an integrated identity, and moving toward goals and a positive future. In essence, prioritizing positive youth-adult relationships breeds future relationships, and potentially a cascade of other positive outcomes.

Taken together, these findings inform an important implication for clinical practice: the critical need to prioritize stability and consistency in early caregiving relationships. Yet, these studies indicate that it is also important to consider lifespan relational needs for this population. For youth participants, caregivers continued to play an important role in their lives well into adulthood. Parenting young people with diverse needs can be challenging, and caregivers will also require multi-system support in order to provide ongoing stable, affirming, and encouraging care to their children. Youth and caregivers may also benefit from efforts to expand youth-adult relational networks beyond caregivers to ensure that youth with FASD have positive connections to adults in their schools and communities. As youth transition to adulthood, it will be important to work toward increasing relationship capacities within adult systems of support – for example, by implementing relationship-centered individual formal services and programming (e.g., mentorship programs). It will also be valuable to support individuals with FASD to grow their

connections to others in healthy and individually-valued ways, such as by ensuring access to FASD-informed family-based therapy for couples and parenting. Future research in this area could include investigating factors that support resilience in caregivers, families, and even teachers so that relationships can be effectively leveraged to support youth with FASD.

Context Matters

The role of contextual resources and a supportive environment (e.g., supportive schools, healthy communities) in encouraging both resilient and thriving trajectories has been well-established in the broader literature (for reviews, see Benson & Scales, 2009; Masten & Cicchetti, 2016). Given that individuals with FASD tend to have multiple support needs that cross several systems of care, many have contended that a supportive environment is essential in this population. The results of Study 1 and 2 support this contention.

In Study 1, youth with FASD and their caregivers reported fairly low contextual resources. These included resources pertaining to education, spirituality, and community/cultural connection. This is similar to findings of other studies using the CYRM in high-risk populations, including youth with FASD (e.g., Rogers et al., 2013). Although contextual resources were low, their presence was associated with better youth adaptive functioning. Similarly, a key finding of Study 2 was that elements of context were an essential precondition to thriving. In Study 2, participants described an indisputable need for contextual support that crossed multiple domains, including academics, employment, independent living, and government financial support. According to participants, contextual support nurtured thriving when it was responsive to youth's unique individual needs, and when its provision was guided by the understanding that youth challenges reflect a poor individual-environment fit. Participants also underscored the need for ongoing contextual support from childhood into adulthood.

These studies add to a growing literature indicating that appropriate environmental support helps youth with FASD navigate toward healthier outcomes (e.g., Denys et al., 2011; Duquette et al., 2006; Job et al., 2013; Millar et al., 2017). Yet, individuals with FASD continue to face multiple barriers in accessing contextual supports, including systemic factors (e.g., poor continuity of care between youth and adult systems; not meeting IQ-based qualifications for disability funding; Petrenko et al., 2013); stigma (Choate & Badry, 2019); and presenting with complex needs that require wrap-around services (Wolfson et al., 2019). These findings support concerted efforts and policy initiatives to remove these barriers. Youth with FASD should be supported with services that are individually customized; that grow and change with them into adulthood; and that address challenging behaviours with supportive environmental solutions.

Future research could examine a broader scope of protective and promotive contextual resources; how contextual resources may relate to positive adaptation; and what can be done to strengthen them. For example, two related elements of context that were not addressed in depth in Study 1 and 2 are cultural connection and spirituality. Although neither Study 1 nor 2 set out to study resilience and thriving from an Indigenous perspective, the majority of youth who participated identified as First Nations youth living in non-biological homes. Understood within this context, the low cultural and spiritual resources reported in Study 1 and the limited discussion of culture and spirituality in Study 2 are notable. As a legacy of colonialism, Indigenous peoples in Canada experience pervasive and ongoing inequalities in numerous social determinants of health (Truth and Reconciliation Commission of Canada, 2015). As a result, Indigenous peoples are more likely to experience health problems, as well as poorer access to resources that may help address problems and support health (Reading & Wien, 2009). For example, being raised in foster care appears to place youth at-risk for numerous adverse emotional, behavioural, and physical health outcomes (e.g., Gypen et al., 2017). For Indigenous

youth especially, being raised disconnected from families and communities of origin also results in being deprived of resources that have been associated with resilient and optimal/self-actualized functioning across many communities and cultures worldwide: connection to cultural practices and spirituality or religiosity (e.g., Hardy et al., 2018; King et al., 2011; Pelech et al., 2013; Toombs et al., 2016). Making concerted efforts to address social determinants of health – for example, by ensuring that Indigenous children with and without FASD grow up with access and connection to their people, culture, and spiritual practices – may help foster healthy individual development and support the recovery of Indigenous communities and cultures (Carriere, 2007; Wolfson et al., 2019).

Individual Qualities and Perceptions of Youth

In the extant FASD literature, examination of youth personal qualities related to resilience has focused mainly on demographic factors (e.g., age, sex) and cognitive limitations (e.g., IQ). In addition, many studies appear to prioritize caregiver- and teacher-report over youth self-report. When youth self-report is included, there is often inconsistency in reporting between youth and key adults (e.g., Mariasine et al., 2014).

In Study 1, I examined a broader array of individual resources related to resilience, including prosocial personal qualities (e.g., cooperation, awareness of strengths), feelings of peer connectedness, and social skills. Youth reported themselves to have fairly high individual resources, whereas caregivers reported low youth individual resources. Yet, both youth- and caregiver-reported individual resilience resources were related to better aspects of mental health and adaptive functioning. Although more research is needed, this study suggests that supporting the development of individual capacities such as social competence could help promote emotional and behavioural wellness. Future research could examine how personal capacities and positive self-perception of self and abilities (regardless of whether observers agree) may function

protectively. Furthermore, although discrepancies between youth and caregiver reports on quantitative assessment tools are not uncommon in the FASD literature, few researchers have directly examined the source of these differences and the implications for professional practice. For example, do differences between youth self-report and caregiver-report on quantitative, forced choice, language based questionnaires reflect differences in insight or cognitive functioning (i.e., inaccurate youth self-perception)? Or could differences be due to inadequate measurement? Perhaps these types of tools do not allow some youth with FASD to adequately express their self-perceptions.

It was not a goal of Study 2 to understand the differences between youth and caregiver perceptions. However, Study 2 did focus largely on understanding the perspectives of youth in a deeper way, as well as understanding positive individual qualities of youth. Many of the themes related to youth perception – for example, that youth *feel* connected to others, competent and autonomous, and like they are participating meaningfully. These results indicate the importance of understanding youth's subjective experience of success in addition to external achievement markers and others' perceptions of youth. The results of Study 2 suggest that self-perception of personal strengths and success (even if self-perceptions do not align with normative definitions of success) may reflect a thriving trajectory by supporting growth toward goals aligned with a positive future. In addition, despite variability in cognitive functioning, all youth interviewed were able to describe both their strengths and challenges with insightful and detailed nuance. Taken together, the results of Study 1 and 2 suggest that going forward, it will be important to include youth perspectives, beliefs, and values in clinical practice and research. Eliciting youth's perspectives can offer valuable insight into their current functioning, self-perceptions, and the future they envision. Intentionally seeking youth perspectives using a multi-method approach may allow youth to more fully express themselves. For example, in practice I would recommend

combining standardized self-report questionnaires of mental health and behaviour with a thorough youth clinical interview, including direct follow-up questions about responses on forced-choice questionnaires. As clinicians and researchers, we must endeavor to treat differences in reporting as something interesting to understand, discover, and integrate rather than something to avoid or dismiss. Ultimately, integrating the voices of youth with information provided by important adults in youth's lives may be key to meaningfully engaging youth, building mutual definitions of success, and setting goals that youth will care about working towards.

Holistic, Individualized, and Integrated Understanding of Individuals

This dissertation began with the assertion that our conceptualization of FASD must evolve from focusing on deficits and limitations to include understanding of how individuals function as a whole. The findings of Study 2, in particular, support the use of person-centered approaches that intentionally seek a holistic perspective of individuals and recognize how strengths, weaknesses, needs, goals, and perspectives of individuals and important others interact. In Study 2, each youth had their own unique challenges, needs, strengths, and goals that were considered in defining and supporting thriving.

Clinically, to improve our holistic understanding of individuals with FASD, we must improve how we assess individual strengths. The findings of Study 2 support broadening the conceptualization of strengths beyond functional strengths, skills, and interests. It is important to also consider passions (or *sparks*) that invigorate youth with a sense of vitality and purpose, as well as unique "abilities within disability." We can also consider more abstract strengths, such as having positive or growth-oriented beliefs or narratives about oneself, or an integrated sense of one's experiences with challenges or disability. An important part of assessing strengths is considering how they function in youth's lives. This allows strengths to be actioned into opportunities for thriving. For example, enacting strengths in different contexts (e.g., work,

recreation, volunteerism) can be used to encourage the development of autonomy, competence, meaningful participation, and contribution. Of course, identifying and understanding strengths does not negate assessing for needs and limitations. Indeed, failure to adequately assess or consider pertinent impairments can be harmful and render supports ineffective.

The results of Study 2 also indicate that a holistic understanding of individuals with FASD requires individualized goals and definitions of success. These findings align with the recommendations of an eminent disability scholar, Wil Buntinx, who argued that developing and delivering effective supports for individuals with disabilities requires "an individualized process" organized around each person's "desired life experiences, ambitions, and wants, as well as… objectified support needs and needs intensities" (Buntinx, 2013, p. 16). Effectively, individuals with FASD have a right to be considered successful within the boundaries of what they are capable of and what is individually-meaningful to them. This may not always align with developmentally-typical markers of success. Clinicians and educators must endeavor to work collaboratively with individuals and families to set goals and intervention targets framed within this context.

Mental Health and Well-Being

Prenatal alcohol exposure appears to be a risk factor for the development of mental health problems (Pei et al., 2011). Thus, it is important to understand factors that may attenuate the risk of developing mental health comorbidity among youth with FASD. In Study 1, mental health symptomology reported for youth with FASD was higher than average. Greater individual resilience resources were associated with less mental health symptomology. Although we could not fully delineate the nature of this association (e.g., does having greater individual resources protect against mental health symptomology, or did participants have greater individual resources because they had less mental health symptoms?), it bears investigating further whether

developing individual competencies such as social skills and peer connections can support the mental health of youth with FASD.

Many Study 2 participants spoke about youth's challenges with mental health. However, experiencing ongoing mental health problems did not necessarily preclude thriving. Many youth viewed their mental health challenges (as well as having FASD) as an experience that gave them strength and allowed them to connect with and help others. For some, accomplishing their goals in light of challenges associated with disability and mental health comorbidity was meaningful. These experiences taught youth that they were capable of working hard and persisting to overcome challenges. In a way, this is the ultimate in adaptation and actualization: transformation of a "burden" into meaning and growth.

There is little doubt that mental health comorbidity can impose a great deal of stress and challenge on individuals and families. However, the findings of Study 2 support an enhanced understanding of mental health symptomology. Mental health symptoms do not have to be exclusively a marker of poor functional outcomes. Clinically, we must work to understand how individuals make meaning out of their experiences with mental health challenges – for example, how individuals subjectively see success in their journey toward transcending and transforming difficulties even if reported symptomology remains higher than average.

A future avenue to explore in research and clinical practice is the idea of positive mental health. Positive mental health is not simply the absence of psychopathology (Keyes, 2005); it also reflects a state of well-being, which includes positive emotions and life satisfaction. In Study 2, feeling happy was a key indicator of thriving with FASD. Yet, subjective well-being is not routinely explored in developmental disability populations. Clinical efforts and future research may begin by examining factors that contribute to the experience of positive emotions and life

satisfaction among individuals with FASD, as well as including well-being as a key outcome variable in intervention research.

Beyond Adaptive Functioning

Individuals with FASD tend to struggle with acquiring skills for daily living and milestones related to independence compared to their typically developing peers (Mattson et al., 2019). There is some understanding of the risk factors related to poorer adaptive functioning (e.g., overall neurodevelopmental impairment, postnatal trauma; McLachlan et al., 2020), but less is known about factors that may promote better adaptive functioning. In Study 1, youth with higher individual and contextual resources were reported to have better adaptive functioning. Although, again, the direction of this association could not be determined, future research could examine if developing individual and contextual resources can support the development of adaptive functioning skills.

In Study 2, I learned that goals related to adaptive functioning were important to youth with FASD and their caregivers, including independent living, financial goals, academic accomplishments, and social/relational goals. However, the process of pursuing adaptive functioning goals – regardless of accomplishment – was equally important. For participants, developing skills held greater meaning than simply accomplishing developmentally-normative milestones. The process of developing competence allowed youth to feel mastery and autonomy over themselves and their environments. It seemed to allow them a sense of self-determination. As discussed previously, participants in Study 2 conceptualized adaptive living success within the context of individually-meaningful goals and individual/environmental capacities and resources. Together, the results of Study 1 and 2 support focusing on growth in adaptive functioning as an important clinical target. Intervention outcomes and successes should be framed in reference to personal goals and individual and contextual capacities and needs.

Adversity and Growth

Numerous studies have found that individuals with FASD are more likely to experience early life adversities, such as neglect and trauma (Kambeitz et al., 2019; McLachlan et al., 2015; 2020; Streissguth et al., 2004). The sample that participated in Study 1 was no exception. In this study, exposure to multiple forms of postnatal adversity was not associated with levels of resilience resources, suggesting a capacity for growth in resources supportive of resilience even in the context of adversity. On the other hand, achieving early stability in living arrangement and receiving an early diagnosis was associated with greater relational and contextual resilience resources. This lends support to other research documenting a link between caregiver stability, early diagnosis, and a reduction in negative outcomes (e.g., Streissguth et al., 2004). In other words, it is possible for subsequent positive experiences to attenuate the risk imposed by early adversity. Most risk and resilience studies in the FASD literature, including Study 1, examine multiple risks. Many focus on how risks tend to accumulate to contribute to negative outcomes. Few studies examine resources associated with resilience, as I did in this study. It is possible that just as risk accumulates, so too could positive potentiators of growth and resilience. Moving forward, it would be interesting to examine cumulative protection. That is, to examine how different factors combine to produce the *best* outcomes instead of the *least bad* outcomes. Future goals of FASD resilience research could mirror developments in the broader resilience field by examining developmental cascades in greater depth. This would involve examining how primary challenges associated with FASD can spread across domains of functioning over time, influenced by the interaction between the individual, their family, and other systems. For example, when a child with FASD is emotionally and behaviourally dysregulated in school, this can negatively affect their academic performance and their relationships with peers and teachers. This may in turn affect self-concept, self-esteem, positive identity formation, and ultimately contribute to

increased mental health symptomology. Identifying where in the negative cascade potential protective factors could effectively intervene (e.g., responsive environment; supportive teachers) and divert the cascade in another direction could prove helpful. Examining the mirror image of this – positive cascades – could be another avenue of research. For example, studying how nurturing a strength in one area could have positive effects across multiple areas.

In Study 2, youth and caregivers reported that youth had experienced multiple challenges, including being raised in non-biological homes, academic difficulties, and mental health problems. Even though many of these challenges were ongoing, youth with FASD in Study 2 were considered thriving because they were persisting through challenges and committing to growth. For example, they were continuing to work toward individually-meaningful goals, regardless of accomplishment. Participants spoke about how avoiding negative outcomes (i.e., an aspect of resilience) was important, but that thriving involved envisioning a positive future and taking deliberate steps toward that future. To accomplish this, youth must believe they are fundamentally capable of growth and change. Similarly, caregivers described understanding their children to be capable of growth and change, and they encouraged youth to grow by setting expectations in accordance with each youth's individual and environmental capacities. This "growth mindset" held mutually and interactively by youth and caregivers may be an incredibly powerful element of thriving with FASD. I believe it bears further exploration. For example, future research could explore the extent to which individuals with FASD and key adults who support them believe youth's challenges to be immutable *versus* changeable, and how this affects youth development. Clinically, interventions targeting these mindsets (i.e., for youth and adults who support youth) may also be helpful.

Final Thoughts

CHAPTER 5: CONCLUSION

FASD is life-long and irreversible. Studying FASD from a resilience and thriving perspective promotes acceptance, hope, and a focus on growth. It "allows us to learn from those who have coped well to promote effective management of the disorder and the establishment of positive qualities and environments that can support both short- and long-term well-being" (Climie et al., 2013, p. 114). The findings of this dissertation help propel a shift from focusing on disorder and deficits toward a holistic and integrated understanding of individuals with FASD. This includes identifying individual, relational, and environmental strengths, achievements, and experiences that can be supported, built upon, and ultimately celebrated. It also involves empowering individuals with FASD to define what it means to be healthy and successful on their own terms.

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Appendix A

THRIVING WITH FASD
YOUTH INTERVIEW

- This should take 30-45 minutes. Please Let me know if you need a break.

- I'm asking these questions because I want to try to find out what it means for people with FASD to thrive, succeed, or do really well

- I want to know what you think

- The questions might seem confusing or like I'm looking for a right answer. But there isn't a right or wrong answer. I just want to know what you think. Don't worry if you're not sure. Just let me know if you don't understand what I'm asking you.

Q1. Tell me a little bit about yourself – your name, how old you are, family, job, school?

Q2. What do you really like doing right now? What do you like about [that]?

Q3. Tell me about what is most important to you in your life right now. Why is it important?

Optional prompts: What is your favorite part of your day? When are you most happy?
Optional prompts: School? Work? Hobbies? Friends? Family? Relationships? Religion/spirituality? Community?

Q4. Tell me about a time when you were doing really well.

What kinds of things were you doing?
How were you feeling?

Q5. ***Preamble: Do you ever think about getting older? Or think about the future? What kinds of things you'd like to do, the kind of person you'd like to be, what you want your life to look like, things like that?***

If you picture yourself being really successful or doing really well when you're older/a grown-up/done high school, what kinds of things do you picture yourself doing?

Optional prompts: School? Work? Hobbies? Friends? Family? Relationships? Religion/spirituality? Community?

Q5a. What kind of person (e.g., personality) would you be?
Q5b. What kinds of things would you have done ("accomplishments?" or goals)
Q5c. How would you be feeling?

Q6. ***Preamble: Do you know anyone else with FASD who is your age or older than you?***

If YES: **Do you think that this person is thriving or doing really well in life?**

If yes: Tell me about them. What about them shows you/tells you that they are thriving or doing really well?

If no: Why not? What could someone like them do to be successful or do really well?

If NO*:* ***Have you heard a story about someone with FASD who is thriving or doing really well? Or can you imagine someone?***

Tell me about them. What about them shows you/tells you that they are doing really well?

Q7. Is there anything you'd like to tell me that I forgot to ask? Anything you would like to add on the topic of what it means to thrive, do really well, or succeed with FASD?

Q8. Is there anything I didn't ask you about this topic that you wish I would have asked?

THRIVING WITH FASD
CAREGIVER INTERVIEW

- This should take 30-45 minutes. Please let me know if you need a break.

- The purpose of these questions is to try and start to figure out what it means for youth with FASD to thrive, succeed or do really well

- The questions are kind of abstract, and might be confusing at times. It might seem like I'm looking for a right answer. But there isn't a right or wrong answer. I just want to know what you think. Please let me know if you don't understand the questions.

Q1. Can you tell me a little bit about [youth's name]? Tell me their story. How are they doing right now?

Q2. What do they really like doing right now? What do they like about [that]?

Q3. What do you think is the most important or meaningful thing to *[youth's name]* right now? Why is it important?

Optional prompts: What's [X's] favorite part of their day? When are they most happy?
Optional prompts: School? Work? Hobbies? Friends? Family? Relationships? Religion/spirituality? Community?

Q4. Tell me about a time when *[youth's name]* was doing really well.

Optional Prompts:
What kinds of things were they doing?
How did they act?
What was going on?
How could you tell they were doing really well?
When was a time you were most proud of them?

Q5. If you imagine *[youth's name]* doing really well in life when they are older, what would they be doing?

What kinds of things would tell you that they are doing really well? That would be markers of thriving or success?

Optional prompts: School? Work? Hobbies? Friends? Family? Relationships? Religion/spirituality? Community?

Q5a. What would they be like (e.g., personality, behaviour, skills)?
Q5b. What kinds of things would they have accomplished?
Q5c. How would they be feeling?

Q6. Do you know of anyone with FASD (personally, or that you have heard stories of) that you think is thriving or doing really well?

If yes: Tell me about them. How can you tell that they are thriving or doing really well?
If no: If you imagine a youth with FASD growing up to thrive or do really well, what would they be like? What would they be doing, what kind of skills/qualities would they have?

Q7. Is there anything you'd like to tell me that I forgot to ask? Anything you would like to add on the topic of what it means to thrive, do really well or succeed with FASD?

Q8. Is there anything I didn't ask you about this topic that you wish I would have asked?